

Patient Activation of Chronic Disease Care in Nursing Research: A Descriptive Study

Kronik Hastalık Bakımında Hasta Aktifliğinin Hemşirelik Araştırmalarında Kullanımı: Tanımlayıcı Araştırma

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ABSTRACT Objective: Patient activation is linked to the self-management of chronic diseases. This study aimed to analyze the research landscape and hotspots of patient activation in chronic diseases care management. **Material and Methods:** This study was conducted descriptive and bibliometric methodology in August 2024. Data were obtained from the Web of Science Core Collection database using the keywords “patient activation” and “chronic disease” along with their Medical Subject Headings combinations. A total of 235 articles were retrieved without year limitations. After applying the filters, 221 publications were included in the analysis. We performed analyses in R Studio using the Biblioshiny package. Descriptive bibliometric analyses of authors, sources, publications, and keywords were summarized and visualized. **Results:** From 1980 to 2024, 221 publications were identified. A total of 1,698 authors and 722 institutions from 28 countries contributed to research on patient activation in chronic disease management. Most publications occurred in 2018. Judith Hibbard emerged as the most productive author, contributing 9 publications. Keywords analysis highlighted “care”, “outcomes”, and “self-management” as the top recurring terms. **Conclusion:** This bibliometric analysis provides a comprehensive overview of the research landscape and trends in patient activation for chronic disease care management. The increasing number of scientific reports highlights growing interest in evaluating patient involvement over time, emphasizing its importance in improving chronic disease outcomes.

Keywords: Chronic illness; nursing; patient activation; self-care

ÖZET Amaç: Hasta aktifliği, kronik hastalıkların öz yönetimi ile ilişkilidir. Bu çalışmada, kronik hastalıkların bakım yönetiminde hasta aktifliğine yönelik araştırma alanı ve öne çıkan konuların analiz edilmesi amaçlanmıştır. **Gereç ve Yöntemler:** Bu araştırma, tanımlayıcı ve bibliyometrik analizler kullanılarak Ağustos 2024'te gerçekleştirilmiştir. Araştırmanın verileri “patient activation (hasta aktivasyonu)” ve “chronic disease (kronik hastalık)” anahtar kelimeleri ve bunların Tıbbi Konu Başlıkları kombinasyonları kullanılarak Web of Science Core Collection veri tabanından elde edilmiştir. Yıl sınırlaması olmadan toplam 235 makale bulunmuş ve filtreler uygulandıktan sonra 221 yayın analize dâhil edilmiştir. Analizler, R Studio’da Biblioshiny paketi kullanılarak gerçekleştirilmiştir. Konu ile ilgili öne çıkan yazarlar, dergiler, yayınlar ve anahtar kelimelere ilişkin tanımlayıcı bibliyometrik analizler özetlenmiş ve görselleştirilmiştir. **Bulgular:** 1980 ile 2024 yılları arasında 221 yayın analiz edilmiştir. Kronik hastalık yönetiminde hasta aktifliği üzerine yapılan araştırmalara 28 ülkeden 1.698 yazar ve 722 kurum katkıda bulunmuştur. En fazla yayın 2018 yılında gerçekleştirilmiştir. Judith Hibbard, 9 yayın ile en üretken yazar olarak öne çıkmıştır. Anahtar kelime analizi, “care (bakım)”, “outcomes (sonuçlar)” ve “self-management (öz yönetim)” terimlerinin en sık tekrar eden kavramlar olduğunu göstermiştir. **Sonuç:** Bu bibliyometrik analiz, kronik hastalık bakım yönetiminde hasta aktifliği araştırma alanı ve eğilimlerine dair kapsamlı bir bakış sunmaktadır. Bu alandaki yayınların sayısının, zamanla artması kronik hastalık yönetiminde hasta aktifliğine yönelik artan ilgiyi vurgulamakta ve bunun kronik hastalık sonuçlarını iyileştirmedeki önemini ön plana çıkarmaktadır.

Anahtar Kelimeler: Kronik hastalık; hemşirelik; hasta aktifliği; öz bakım

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Chronic diseases are persistent, long-term conditions that are generally manageable but not curable. Patients with chronic diseases often have to cope with daily symptoms that impact their quality of life and may face sudden health issues and complications that could shorten their lifespan.¹ The number of adults with chronic diseases has increased in recent years. At a global level, seven of the 10 leading causes of deaths in 2021 were noncommunicable diseases.² It is estimated that 16-57% of adults in developed countries have multiple chronic diseases, which leads to higher morbidity, mortality, and lower quality of life.³ Patients with chronic diseases often have inadequate medical management, more complications, and unnecessary hospitalizations.⁴ The activation level of patients with chronic diseases is low, making it challenging for them to effectively integrate into the chronic disease self-management system.⁵ Patients with chronic diseases often have to act as their own primary caregivers, taking responsibility for daily disease management, implementing lifestyle changes, managing their emotions, and accurately reporting their condition.^{6,7} This positively influences self-management skills of patients with chronic diseases.⁵

Self-management is a key strategy for alleviating the burden of disease in both patients and the healthcare system as well as for reducing mortality among patients with chronic diseases. It plays a crucial role in improving health outcomes and reducing overall healthcare costs.⁸ A lack of self-management knowledge has been identified as a risk factor contributing to poor health outcomes in patients with chronic diseases.⁴

Patient activation is linked to the self-management of chronic diseases. As increasing level of the patient activation, patients are more likely to engage in self-management behaviors that lead to better health outcomes.^{9,10} Patient activation refers to the knowledge, confidence, and skills necessary for managing chronic diseases, and is a precursor to effective self-management. Increasing a patient's knowledge, confidence, and skills supports better management of chronic diseases and improves overall health outcomes.^{11,12} Patient activation involves a set of skills that enables patients to understand health information and make informed decisions about their healthcare.¹³

When patients stay engaged, take steps to maintain their health, and play an active role in their care, even during stressful times.¹⁴

Patients with higher levels of patient activation are more likely to engage in self-management behaviors, have fewer unmet medical care needs, and seek support from healthcare professionals.^{12,15} The Patient Activation Measure (PAM) is designed to assess a person's level of activation in managing their disease. Studies utilizing PAM have indicated that higher scores are linked to increased activation, and self-management can enhance blood glucose control, improve diet and exercise, support smoking cessation, and aid in weight management.¹⁶⁻¹⁸ A recent meta-analysis showed that patients with higher activation levels had a reduced risk of hospitalization. In addition, patient activation can affect medication adherence and overall disease management.¹⁹ Therefore, enhancing patient activation can improve chronic disease self-management.¹⁵

Patient activation is a modifiable and flexible process that can increase or decrease over time.²⁰ Patient activation interventions that enhance self-management are crucial for the management of chronic diseases.⁸ Patient education, an intervention to increase patient activation, self-care knowledge, and chronic disease management, improves health outcomes among patients with chronic health conditions by increasing the level of patient activation.²¹ Planning interventions, such as patient education that assesses and enhances patient activation levels, are crucial for effectively managing chronic diseases.

This study aimed to perform a comprehensive bibliometric and visualization analysis to determine the research landscape and hotspots of patient activation in chronic disease management. The following 4 questions are discussed in this descriptive study: (i) What are the overall publication trends of patient activation in chronic disease management studies worldwide? (ii) Which authors, their countries, and affiliations are the most influential in terms of the number of publications and citation analysis? (iii) Which sources are most influential in terms of the number of publications and citation analysis? (iv)

What are most frequently used keywords and trending topics in these studies?

MATERIAL AND METHODS

DESIGN

This descriptive study was conducted using a bibliometric methodology. This bibliometric analysis was performed in the R program using data obtained from the Web of Science Core Collection (WoSCC) database. In this study, we performed the following steps: (1) Data Collection, (2) Data Analysis, (3) Data Interpretation, and (4) Data Visualization. In these steps we applied Search, Appraisal, Synthesis, and Analysis (SALSA) method. This methodology ensures precision, systematic organization, comprehensiveness, and reproducibility. The SALSA method was applied to generate unbiased datasets during the data processing stages and to accomplish the research objectives, which encompassed both the search and analysis steps (Figure 1).

PARTICIPANTS/SAMPLE

No human participants were included in the study as the study data were obtained from the WoSCC database. The study was conducted by examining 221 studies in the field of nursing related to the patient activation and chronic disease care.

DATA COLLECTION

For data collection, we followed 4 sub-stages. These are the determination of search keywords, data retrieval, data cleaning, and data loading. Firstly we determined the searching keyword, that was “patient activation” and “chronic disease” and their Medical Subject Headings combinations. In the 2nd stage, we searched the papers by entering these terms in the WoSCC database on August 05, 2024. We obtained 235 articles without a year limitation. To ensure that relevant and representative publications were included, we applied filters. The search strategy included the following terms without year limitation: (i) Topic=“patient activation” OR “patient activity” OR “patient activ*” AND Topic=“chronic disease” OR “noncommunicable disease.” (ii) Subject area=Nursing, (iii) Language=English, (iv) Document type=Article OR Review Article. After limitations considered we exported 221 relevant publications in bibTex format, including full records and cited references, to conduct further analyses. We loaded all publications into the R program for analysis.

DATA ANALYSIS

The data were analysed using the open-source statistical tool R (v.4.4.1 for Windows). We used bibliometrix codes to perform this bibliometric study and

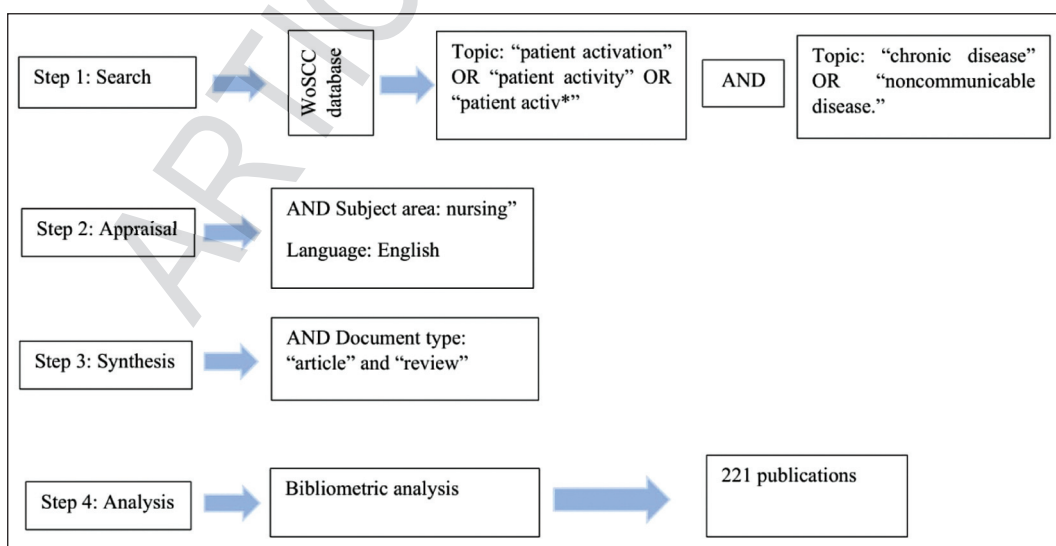


FIGURE 1: SALSA steps of data analysis and selection process
WoSCC: Web of Science Core Collection

matrix table in the R program. The bibliometrix R package is an open-source environment offering a range of tools for quantitative research in R. The bibliometrix code has a web-based interface called “biblioshiny”.²² We used biblioshiny for the analysis.

DATA INTERPRETATION

There are several important data interpretation approaches in bibliometric studies. We conducted a descriptive analysis and network extraction in the R program using biblioshiny. We interpreted the data through main categories the following details: we interpreted the data through main categories in the R program the following details: descriptive bibliometric analyses, sources (most relevant sources, most cited sources), authors (most relevant authors, most cited authors, authors’ production over time, corresponding author’s countries, most cited countries, most relevant affiliations, affiliations’ production over time), documents (most cited documents), and words (most frequent words, wordcloud, trend topics).

DATA VISUALIZATION

In this study, we created 3 visualization figures: country production over time, wordclouds, and trend topics.

ETHICAL CONSIDERATIONS

Ethics committee approval was not obtained in this study as it had no direct effects on humans and was a bibliometric analysis.

RESULTS

DESCRIPTIVE BIBLIOMETRIC ANALYSIS

We analyzed 221 publications from 132 scientific journals written by 1,698 authors related to patient activation in chronic diseases. The types of the peer-reviewed scientific publications were articles (n=206) and reviews (n=15). The articles were published between 1980-2024. When we examine annual scientific production, we could describe 3 main time phases. To date, the number of relevant publications has shown significant growth. The 1st phase is called the nascent development stage (1980-2008). Initially, one article was published in this field, which contin-

ued for many years without any articles being published. In the 2nd phase (2009-2016), which can be called the gradual development phase, up to 17 publications were published within a year. Between 2017 and 2023, the number of publications on this topic significantly increased. This 3rd phase may be called the rapid growth period, and the maximum number of publications was reached between these years. When we examined all periods, the annual growth rate was 5.37%, and the average number of citations per document was 45.19.

AUTHORS OF THE PUBLICATIONS

We examined the authors, their countries, and affiliations in the analysis. A total of 1,698 authors were involved in this study regarding patient activation, resulting in an average of 8.36 authors per article. The 10 most productive authors are listed in Table 1. According to the table, Hibbard had the most publications (n=9), followed by Hudon C (n=5), and Harris, Hibbard, Kephart, Lussier, Wegener who all had 9 publications.

We examined the geographical distribution of publications on patient activation in chronic diseases. The total number of countries whose corresponding authors were analyzed was 28. The United States, with 110 publications, was ranked 1st. Canada, with 26 publications, and Australia, with 16 publications, followed the USA. Furthermore, except of 2 countries (Spain and Iran), all of the top countries were also the top-cited countries. Figure 2 shows the countries’ production over time.

TABLE 1: The top 10 most productive authors

Authors	Number of publications	Number of publications fractionalized
Hibbard JH ^{9,14,16,17,31}	9	1.65
Hudon C	5	0.91
Harris MF	4	0.77
Hibbard J ²³	4	0.58
Kephart G	4	0.59
Lussier MT	4	0.91
Wegener ST	4	0.50
Bout C	3	0.32
Chouinard MC	3	0.45
Greene J ^{16,31}	3	0.70

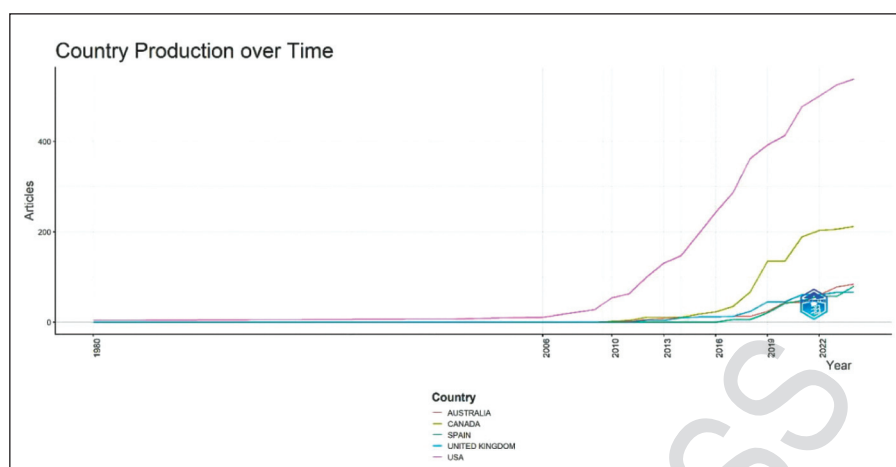


FIGURE 2: Country production over time

We determined that 722 affiliations made significant contributions to our dataset. McMaster University emerged as the most prolific institution, with 24 publications constituting 10.86% of the total literature in this field, and was closely followed by McGill University and University of Oregon.

SOURCES OF THE PUBLICATIONS

A total of 132 academic journals contributed to this field. We listed the top 10 journals that published the largest number of studies on patient activation in nursing from 1980 to 2024 (Table 2). The leading 10 journals published 72 studies, constituting 35.58% of the 221 studies retrieved. Patient Education and Counseling ranked 1st with 19 studies, followed by Journal of Medical Internet Research (n=10), and Health Services Research (n=8), respectively. Ac-

cording to the Journal Citation Reports (JCR) 2023 standards, 6 of the top 10 journals are classified as Q1. Patient Education and Counseling was the most cited, with 389 citations. This was followed by Health Services Research with 321 citations, Journal of General Internal Medicine with 222, and Health Affairs with 204 citations. Every journal in the top 10 co-cited journals received more than 100 citations, ninth of which fell into the JCR Q1 category.

ANALYSIS OF PUBLICATIONS

The top 10 publications that received the highest number of citations in our dataset are listed in Table 3. These highly cited articles were published between 2004-2015. The most frequently cited study, authored by Hibbard et al., accumulated 111 citations. Publications by Hibbard et al. and Remmers et al. ranked

TABLE 2: The top 10 journals publishing studies regarding patient activation

Journal	Number of the publications
Patient Education and Counseling	19
Journal of Medical Internet Research	10
Health Services Research	8
BMJ Open	7
Plos One	7
BMC Health Services Research	6
Trials	5
Quality of Life Research	4
Australian Journal of Primary Health	3
BMC Family Practice	3

TABLE 3: Top 10 most cited publications

Cited Publications	Local Citations
Hibbard JH ¹⁴ , 2004, Health Serv Res	111
Hibbard JH ⁹ , 2007, Health Serv Res	58
Remmers C ²³ , 2009, J Ambul Care Manag	27
Fowles JB, 2009, Patient Educ Couns	26
Skolasky RL, 2011, Health Serv Res	19
Brenk-Franz K, 2013, Plos One	17
Solomon M, 2012, J Med Internet Res	11
Marshall R, 2013, J Gen Intern Med	10
Magnezi R, 2014, Plos One	10
Kinney RI, 2015, Patient Educ Couns	10

2nd and 3rd, respectively with 58 and 27 citations, respectively.^{9,14,23} The most frequently cited document is the Hibbard et al. that published in the PAM.¹⁴

ANALYSIS OF KEYWORDS

In this analysis, we determined high-frequency words, word clouds, and trends. High-frequency keywords are crucial research hotspots. The 10 main words with the highest frequency related to patient activation in chronic diseases are listed in Table 4. The word cloud is shown in Figure 3. Apart from pre-defined search words, such as “patient activation”, “patient activity”, and “chronic disease”, the most

frequently occurring words were “care”, “outcomes”, and “self-management.” Based on these words, we can strongly say that publications in this field have mainly focused on increasing the level of self-management and improving care and patient outcomes by increasing the level of patient activation. We determined that the top 7 high-frequency words showed a trend in the rapid growth period.

DISCUSSION

This study used bibliometric analysis to map the field, highlighting significant developments, key topics, and emerging trends in patient activation in chronic disease management. In this study, we analyzed 221 publications from 132 scientific journals written by 1,698 authors related to patient activation in chronic diseases between 1980-2024. When we examined annual scientific production, the number of relevant publications showed significant growth. According to the published literature, the 1st number of publication began in the 1980s and progressed quietly for many years, without any publication, until the end of the 1st decade of the 2000s. The number of publications on patient activation in chronic disease management has increased gradually since 2017. The maximum number of publications was reached in 2018, with 25 publications. This could be related to the development of health and technology. People

TABLE 4: The top 10 most frequent words and analysis of trend topic

Words	Number of occurrences	Trend topic (year)
Care	62	2018
Outcomes	54	2018
Self-management	53	2016
Chronic disease	48	2016
Health	30	2018
Validation	30	2019
Patient activation	27	2019
Activation	23	2017
Quality-of-life	21	2019
Measure PAM	20	2015

PAM: Patient activation measure



FIGURE 3: Word cloud

have longer lives, partly because of advancements in medical science, technology, and healthcare delivery. As the population ages, the number of patients with chronic conditions rises. Although most of the disease burden and healthcare resources are dedicated to treating chronic conditions, the healthcare system remains primarily designed for acute care, which is inadequate for meeting the needs of chronic disease management.²⁴ Developments in society and healthcare systems have highlighted the need for a care approach that extends beyond the traditional healthcare model.²⁵

Studies indicated that effective treatment of chronic conditions requires ongoing coordination between healthcare providers and patients, extending beyond the traditional healthcare model.²⁶ Healthcare providers must work together and with patients to create collaborative care plans that include mutually agreed-upon goals, targets, and actionable steps. Each health plan should be tailored to the patient's socio-cultural context through individualized care approaches.²⁷ To adhere to such a health program, patients must actively participate in healthcare practices according to their own lives and abilities. When care planning takes a personalized approach, patients are empowered to align their care with their unique needs and priorities.²⁸ This activation enables patients to set recovery goals that address not only their symptoms, but also other aspects of their lives that contribute to their overall well-being.²⁹ These developments indicate that approximately 40% of people with chronic diseases desire additional support to manage their health and well-being on a daily basis. This situation has remained largely unchanged over the past decade.³⁰ It is inevitable that these developments within the social structure and healthcare system reflect the scientific environment. Our study shows that publications relevant to patient activation in chronic disease care should be enhanced.

We examined the authors; Hibbard was the most productive author, with 9 of the 1698 authors. Hibbard et al. developed PAM to measure patient activation and presented compelling evidence that improved patient activation is linked to better health-related outcomes.^{14,31} This measurement tool, which provides reliable results for the evaluation of patient

activation, has been used to evaluate the activation level of patients with different chronic diseases.^{9,32}

Among the 28 countries and regions, the United States, with 110 publications, ranked 1st, with more than 4th the number of publications compared to 2nd-ranking Canada. The English language is spoken in the first 4 countries with the highest number of publications. The advantage of using the English language might have led to the publication of a greater number of publications. Although it is published more frequently in America, Canada, and Western European countries, it is less common in Asian countries. China ranked 1st among Asian countries in terms of publication. This finding highlights China's increasing impact on patient engagement. To create a more balanced and collaborative environment in this field, it is essential to strengthen cooperation among countries, especially developing nations. All the top 10 affiliations in study numbers are in the United States and Canada. Both countries underscore their dominant role in patient activation in chronic disease management studies. It is thought that the top 10 universities that contribute to scientific publications in this field are in America and Canada, and that these 2 countries are geographically close and can speak English to help accelerate their communication. Moreover, the fact that Hibbard, the most productive author in this field and one of the developers of the PAM, currently works in America, her affiliation ranked 3rd among the top 10 most productive affiliations, likely contributed to the acceleration of scientific collaboration.

According to the JCR 2023 standards, 6 of the top 10 journals are classified as Q1, proving the high quality of research in this field. The first 3 keywords most frequently used in articles in this field are "care," "outcomes" and "self-management," respectively. It is predicted that as a patient's activation status improves, their self-management in care practices will increase, and patient outcomes will improve. Therefore, it is necessary to evaluate the impact of patient activation level on the evaluation of care, self-management level, and patient outcomes. For this reason, PAM, which is a questionnaire evaluating the level of patient activation, was frequently used in publications and was among the 10 most frequently

used words. Furthermore, the most frequently cited publications, authored by Hibbard et al. published PAM. Patient Activation Measure is a reliable tool that evaluates the patient activation level and determines the impact of changes in the activity level on patient outcomes.^{14,31} Therefore, it is frequently used to evaluate the activation levels of patients.

LIMITATIONS

This study outlined the research landscape and hotspots of patient activation in chronic disease management. However, this study has some limitations. The analysis included only publications from the WoSCC database and only English-language publications were considered. As a result, not all journals may be indexed in the WoSCC, and some relevant research could be published in non-indexed or non-English-language journals.

CONCLUSIONS

This study could help researchers and healthcare professionals access scientific information regarding the most productive authors, countries, institutions, and journals that accept the most research in this field. Increasing collaboration with authors, countries, and universities in this field could help balance growth in publications and improve patient access to initiatives

related to patient activation. The management of chronic diseases can be achieved by increasing the level of patient activation. It may be recommended to evaluate the level of patient activation using PAM and implement interventions to increase patient activation.

Source of Finance

During this study, no financial or spiritual support was received neither from any pharmaceutical company that has a direct connection with the research subject, nor from a company that provides or produces medical instruments and materials which may negatively affect the evaluation process of this study.

Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

Idea/Concept: Ferya Çelik, Hicran Bektaş; **Design:** Ferya Çelik, Hicran Bektaş; **Control/Supervision:** Hicran Bektaş; **Data Collection and/or Processing:** Ferya Çelik; **Analysis and/or Interpretation:** Ferya Çelik, Hicran Bektaş; **Literature Review:** Ferya Çelik; **Writing the Article:** Ferya Çelik, Hicran Bektaş; **Critical Review:** Hicran Bektaş; **References and Fundings:** Ferya Çelik, Hicran Bektaş.

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