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Longitudinal Studies on Illness Perceptions in Cancer Patients: A Scoping Review

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Abstract: *Objective:* To conduct a scoping review of longitudinal studies related to disease perception in cancer patients and to provide a reference for the improvement of disease perception in cancer patients. *Methods:* Using the scoping method, PubMed, Web of Science, The Cochrane Library, Medline, CNKI, Wanfang Database, VIP Chinese Scientific and Technical Journals Database, and China Biomedical Literature Database were searched up to July 2023 for analysis and discussion of the included literature. *Results:* A total of 19 articles were included, distributed across 9 countries including China, the Netherlands, and the United Kingdom, with 8 articles published in China. The study subjects included patients with breast cancer, colorectal cancer, laryngeal cancer, lung cancer, esophageal cancer, and bladder cancer. The content covered dynamic changes in disease perception, the impact of disease perception, and the influencing factors of disease perception. *Conclusion:* The number of longitudinal studies on disease perception in cancer patients is gradually increasing and becoming more diverse. However, issues such as a small total number of studies, single research methods, and short observation periods persist. In the future, it is necessary to conduct in-depth longitudinal research on disease perception in cancer patients, expand the scope of research fields, and provide more comprehensive theories to guide clinical treatment and nursing practices, ultimately improving the treatment outcomes and quality of life for cancer patients.

Keywords: Illness perception; Cancer; Longitudinal studies; Scoping review

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1. Introduction

According to the report by the International Agency for Research on Cancer (IARC) [1], there were approximately 19.3 million new cancer cases globally in 2020, with about 4.57 million new cases in China [2]. The diagnosis and treatment of cancer, as a stressful event, can significantly affect patients' illness perception. Illness perception refers to the cognitive and emotional responses individuals have towards the characteristics of a disease or their health status [3], a concept developed from the self-regulation model proposed by Leventhal *et al.* in the 1980s [4]. Previous studies have shown that illness perception not only influences patients' quality of life [5,6] and self-management [7,8] but also impacts their long-term survival rates [9], making it a current research focus.

However, there are relatively few longitudinal studies on illness perception among cancer patients both domestically and internationally, and the scope and extent of these studies are unclear. Therefore, this study adopts the scoping review framework proposed by Arksey *et al.* [10] to describe and analyze longitudinal studies on illness perception in cancer patients, aiming to provide a comprehensive understanding of the current research status in this field and to offer valuable insights for clinical practice and future research.

2. Materials and methods

2.1. Research question formulation

Through preliminary literature review and discussions with research team members, the following research questions were identified:

(1) How does illness perception in cancer patients change over time?

(2) What impact does illness perception have on cancer patients?

(3) What factors influence the illness perception of cancer patients?

2.2. Inclusion and exclusion criteria

Inclusion criteria:

(1) Subjects must be cancer patients.

(2) The study must focus on illness perception.

(3) The study must use a longitudinal research design.

Exclusion criteria:

(1) Research proposals, guidelines, opinions, and policy documents.

(2) Studies with incomplete content, duplicate reports, or those where the full text is unavailable.

(3) Non-English or non-Chinese language literature.

2.3. Literature search strategy

A comprehensive search of relevant literature was conducted in PubMed, Web of Science, Cochrane Library, Medline, CNKI, Wanfang Database, VIP Chinese Scientific and Technical Journals Database, and China Biomedical Literature Database. The search period spanned from the establishment of the databases to July 2023. The Chinese search terms included " 癌症 / 癌病 / 恶性肿瘤 ," " 疾病感知 / 疾病认知 / 病情认知 ," " 纵向研究 / 前瞻性研究 / 轨迹研究 / 队列研究 ." The English search terms included "cancer/carcinoma," "illness perception/illness cognition/disease cognition/disease awareness," and "longitudinal study/prospective study/cohort study/trajectory study." A combination of subject terms and free terms was used for the search. To ensure comprehensiveness, references of the included literature were also traced.

2.4. Literature screening and data extraction

The bibliographic records obtained from the search were imported into EndNote X9. Two trained researchers independently screened the literature according to the inclusion and exclusion criteria. Duplicate literature was removed, and irrelevant studies were excluded after reading titles and abstracts, followed by a full-text review to determine inclusion. In case of discrepancies, a third researcher was consulted for discussion and resolution, and reasons for exclusion were documented. Data were extracted based on the research objectives and presented in tabular form, including author, country, publication year, study type, study content, research methods, study subjects, and sample size.

3. Results

3.1. Literature screening results

The initial search yielded 976 articles. Following de-duplication, title and abstract screening, and full-text review according to the inclusion and exclusion criteria, 18 articles were included [11-28]. Additionally, one more relevant article was obtained by tracing references of the included studies [29]. The literature screening process is illustrated in **Figure 1**.

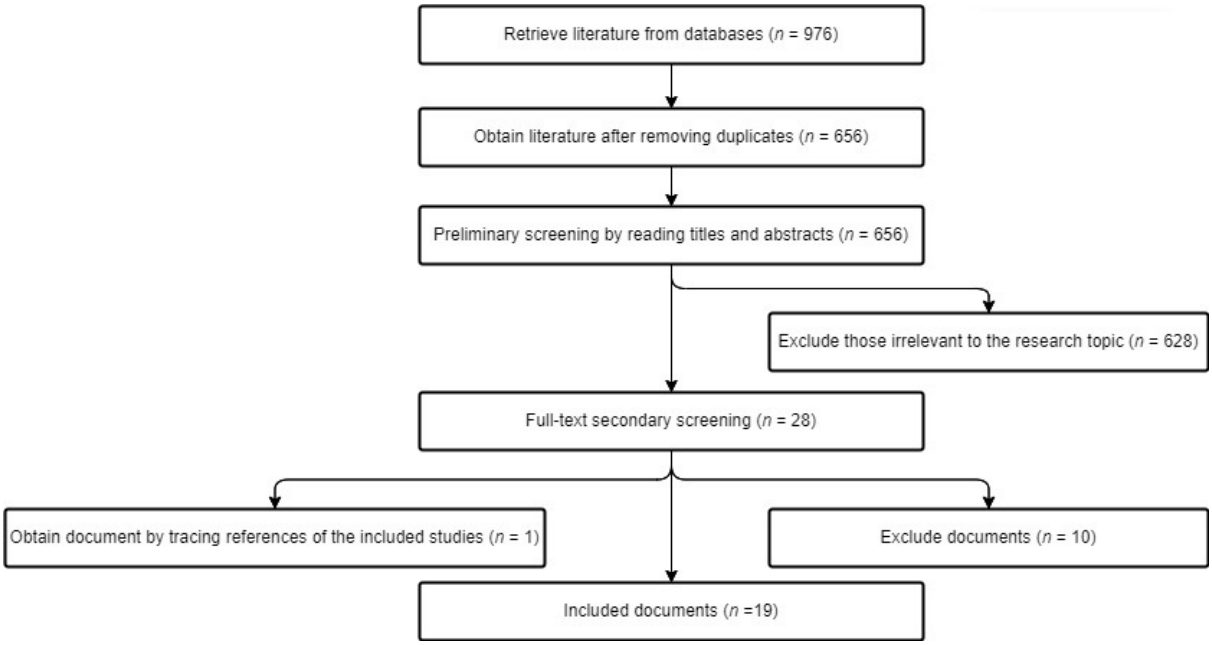

Figure 1. Literature screening process

3.2. Summary of included studies

This review included 19 studies published between 2005 and 2023, from China [11-18] (n = 8), the Netherlands [19-21] (n = 3), the United Kingdom [22,29] (n = 2), Germany [23] (n = 1), Sweden [24] (n = 1), Ireland [25] (n = 1), Denmark [26] (n = 1), Brazil [27] (n = 1), and the Republic of Korea [28] (n = 1). The first longitudinal study on illness perception among breast cancer patients was published in the United Kingdom in 2005 [22], followed by one study from Denmark in 2009 [26]. The year 2020 saw the highest number of publications, with five studies [13,14,17,18,21]. The duration of the longitudinal studies ranged from 3 to 18 months, with a median duration of 6 months. All studies were prospective cohort studies using questionnaire surveys for data collection. Details are provided in **Table 1**.

3.3. Summary of study subjects

Among the 19 included studies, the primary research subjects were breast cancer patients [11,12,19,22,26,28,29], followed by colorectal cancer patients [15-17,24], and laryngeal cancer patients [14,18]. There were also studies on bladder cancer [13], lung cancer [21], prostate cancer [23], and esophageal cancer [25]. The study subjects were all adults, aged between 18 and 98 years. Sample sizes ranged from 21 to 395, with eight studies having fewer than 100 participants, nine studies having between 100 and 300 participants, and two studies having more than 300 participants. Details are provided in **Table 2**.

Table 1. Summary of features of included literature (n = 19)

Items	Number of studies (n)	Proportion (%)
Country		
China	8	42.10
The Netherlands	3	15.79
The United Kingdom	2	10.53
Others	6	31.58
Year		
2023	2	10.53
2022	1	5.26
2021	2	10.53
2020	5	26.32
2018	1	5.26
2017	2	10.53
2013	2	10.53
2012	1	5.26
2011	1	5.26
2009	1	5.26
2005	1	5.26
Study duration (months)		
3	3	15.79
6	7	36.84
12	7	36.84
18	2	10.53
Study type		
Prospective study	19	100.00
Research method		
Questionnaire survey	19	100.00

Table 2. Summary of study subject characteristics (n = 19)

Items	Number of studies (n)	Proportion (%)
Cancer types		
Breast cancer	8	42.10
Colorectal cancer	4	21.05
Laryngeal cancer	2	10.53
Others	5	26.32
Age		
> 18	19	100.00
Sample size (cases)		
< 100	8	42.10
100–300	9	47.37
> 300	2	10.53

3.4. Study content

3.4.1. Dynamic changes in illness perception

Ten studies showed that the illness perception of cancer patients changes dynamically over time [11,14-19,21,25,28], exhibiting different trends. For instance, two studies [15,16] reported a decrease in illness perception levels among colorectal cancer patients, indicating reduced negative illness perception, while Lu *et al.*'s study [17] found the opposite. Changes in illness perception among breast cancer patients varied, with an increase in negative illness perception in the first six months post-surgery [11], a decrease in negative illness perception during a one-year follow-up of patients receiving endocrine therapy [28], and significant changes in three dimensions (disease consequences, personal control, and illness understanding) one year after completing all treatments. Among laryngeal cancer patients [14,18], negative illness perception decreased and positive illness perception increased during a six-month follow-up. Non-small cell lung cancer [21] and esophageal cancer [25] patients showed varying degrees of improvement in illness perception over different observation periods.

3.4.2. Impact of illness perception on cancer patients

Illness perception affects the psychology, quality of life, and self-management of cancer patients. Three studies [19,22,24] reported that negative illness perception exacerbates the distress of cancer patients, and five studies [13,23,25,28,29] found that illness perception leads to anxiety and depression among cancer patients. Additionally, illness perception was negatively correlated with post-traumatic growth in cancer patients. Four studies [16,21,24,26] showed that increased negative illness perception is associated with poorer quality of life, with illness perception mediating the impact on quality of life among colorectal cancer patients. Four studies indicated that illness perception affects self-management behaviors in cancer patients, including lymphedema risk management [12], medication adherence [15,17], and lifestyle [20].

3.4.3. Factors influencing illness perception in cancer patients

Three studies explored the factors influencing illness perception in-depth. Chen *et al.* [11] found that age, education level, marital status, employment status, per capita monthly income, cancer stage, and lymph node removal status were influencing factors among breast cancer patients. Older patients perceived fewer symptoms compared to younger patients, employed patients were more confident in personal control over the disease, and patients with higher education and stage II or higher cancer had a better understanding of the disease. Kern *et al.* [27] found that women had more negative illness perception than men. Park *et al.* [28] found that breast cancer patients under 40 perceived an increased timeline, employed patients had decreased perception of treatment control, and premenopausal or chemotherapy-naive patients perceived more symptoms.

4. Discussion

4.1. Increasing attention on illness perception in cancer patients but limited overall studies

Before 2012, longitudinal studies on illness perception in cancer patients were rare. The number of publications has gradually increased since then, with 10 articles published after 2020 [11-18,21,23,28], indicating growing attention to this area of research. However, compared to cross-sectional studies, the total number of longitudinal studies remains limited. The United Kingdom published the first prospective study on illness perception among breast cancer patients in 2005 [22], followed by the first Chinese study in 2017 [15]. Since 2020, seven such studies have been published in China [11-18], reflecting increasing attention to longitudinal research on illness perception among cancer patients in China. However, issues such as late initiation and short observation periods remain.

Thus, nursing researchers should increase longitudinal studies on illness perception in cancer patients, exploring this topic from multiple aspects.

4.2. Diverse but limited study content and methods

The primary research objectives of the included studies were to analyze the negative impacts of illness perception, its influencing factors, and dynamic changes in illness perception. Researchers explored the impact of illness perception on cancer patients' psychology, quality of life, and self-management. Factors influencing illness perception were analyzed from demographic and disease-related perspectives. Dynamic changes in illness perception were observed during different treatment and follow-up periods. The duration of longitudinal studies varied from 3 to 18 months. All studies employed quantitative methods using questionnaires, lacking qualitative studies to deeply explore patients' true feelings. The preference for quantitative methods may be due to their reproducibility and objectivity in data collection and analysis. Future nursing research should extend observation periods and diversify research methods to comprehensively explore illness perception in cancer patients and improve clinical nursing practices.

4.3. Insufficient study subjects and narrow coverage

Breast cancer patients were the most frequently studied group, followed by colorectal and laryngeal cancer patients. Female breast cancer has surpassed lung cancer to become the most common cancer globally [2], making breast cancer patients a key research population. Additionally, all included studies focused on adult cancer patients, with no reports on pediatric cancer patients, likely due to their immature mental development. Moreover, the sample sizes in the studies did not exceed 400, indicating a lack of large-sample prospective studies. Nursing scholars should conduct large-scale longitudinal studies on illness perception in cancer patients, expanding the breadth and depth of research to better understand their illness perception and provide more effective care and support.

4.4. Nurses should pay close attention to the negative impact of illness perception in cancer patients and intervene promptly

Negative illness perception not only exacerbates patient distress, leading to psychological issues such as anxiety and depression [13,19,22-25,28,29], but also reduces quality of life [16,21,24,26] and affects self-management behaviors [12,15,17,20]. Monitoring and addressing illness perception is crucial for improving prognosis and significantly impacts the treatment and rehabilitation process of cancer patients. Therefore, clinical practitioners must enhance their focus on patients' illness perception, assess it regularly, and implement appropriate interventions to mitigate negative perceptions. Given that illness perception in cancer patients evolves over the course of treatment [11,14-19,21,25,28], healthcare providers should offer tailored support and attention at different stages. By adjusting interventions according to the varying levels of illness perception at different phases, the effectiveness of nursing care and the quality of life of patients can be improved.

5. Conclusion

This scoping review of longitudinal studies on illness perception in cancer patients indicates that illness perception increases patients' distress, causing anxiety and depression, and negatively impacts their quality of life and self-management behaviors. Demographic factors such as gender, age, education level, cancer stage, and lymph node removal status influence illness perception. Additionally, illness perception in cancer patients

dynamically evolves over time, showing different trends. While the number of longitudinal studies on illness perception in cancer patients is increasing, the overall quantity is still limited, with single methods and short follow-up periods being common issues. Nursing researchers should intensify longitudinal research on illness perception in cancer patients to provide comprehensive theoretical guidance for clinical practice and improve treatment outcomes and quality of life for cancer patients. This study only included Chinese and English literature, which may introduce search bias, and did not evaluate the quality of the included literature. Future research should expand the search scope and conduct quality evaluations to obtain stronger evidence.

6. Relevance to clinical practice

The findings of this scoping review hold significant implications for clinical practice, particularly in the realm of oncology nursing. Understanding the evolution of cancer patients' perceptions over time is crucial for healthcare providers to deliver person-centered care that is attuned to the changing needs and experiences of patients. This review underscores the importance of continuous assessment and adaptation of care strategies to align with patients' evolving understanding and emotional responses to their illness. The insights gained from this review can inform the development of targeted educational programs and psychological support interventions that are sensitive to the progression of patients' illness perceptions. For instance, identifying pivotal moments when patients' perceptions significantly shift could allow for timely interventions to address emerging concerns and enhance coping mechanisms.

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