

## REVIEW

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# Unmet Psychosocial Needs and Quality of Life of Young Women with Breast Cancer: A Scoping Systematic Review

Shaza Hasan, Keng Sheng Chew\*

## Abstract

**Background:** The diagnosis and treatment of breast cancer are very distressing for young women and can result in a lot of unmet psychosocial needs and a lower quality of life. **Objective:** Although unmet psychosocial needs in young women with breast cancer can negatively impact their quality of life, these needs have not been systematically reviewed. The primary objective of this scoping review was to identify the categories of unmet psychosocial needs among young women with breast cancer. The secondary objective was to examine the relationship between these unmet psychosocial needs and their quality of life. **Methods:** Five electronic databases (MEDLINE from the National Library of Medicine, Cumulative Index of Nursing and Allied Health Literature (CINAHL), SCOPUS, Web of Science WOS, and Google Scholar), as well as reference lists of relevant literature were systematically searched to identify the relevant literature following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for reporting systematic reviews. **Results:** From an initial yield of 2505 articles, 30 articles were included and analyzed. The results identified 13 main domains of unmet psychosocial needs among young women with breast cancer: information needs, psychological needs, physical/symptoms needs, fear of recurrence and spreading, identity-related needs, social needs, sexual needs, social support, financial support, practical needs, spiritual needs, communication-related issues with health care providers, and coping needs. Data were extracted and summarized in a narrative synthesis. **Conclusion:** Ongoing assessment of informational needs and a clear understanding of the relationship between unmet psychosocial needs and quality of life are essential for healthcare providers to develop robust support systems for young women with breast cancer.

**Keywords:** Young women- unmet- psychosocial needs- quality of life- stigma

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## Introduction

Breast cancer is the most commonly diagnosed cancer and a leading cause of cancer-related death in women worldwide [1]. Historically recognized as a disease predominantly affecting postmenopausal women, its incidence has significantly increased among younger women in recent decades [2, 3].

The diagnosis and treatment of breast cancer are known to be profoundly devastating for women of any age [4]. However, for younger women, the impact can be even more distressing due to its aggressiveness, necessitating intensive treatments such as mastectomy and chemotherapy [5]. The unexpected onset at a young age may also lead to numerous unmet psychosocial needs.

Psychosocial needs in this review are defined according to what has been described in the literature as psychological/ emotional, informational, practical, identity, social, and spiritual needs [6]. Unmet psychosocial needs in cancer patients are defined as those needs that

patients consider important or very important, but they are dissatisfied that these needs are not met [6-8]. These unmet psychosocial needs can adversely affect young women's quality of life and how well they cope with the disease [9-11]. It can also increase their levels of uncertainty, distress, anxiety, and fear, and affect the treatment decision-making processes [12, 13]. Despite its devastating impact on these young women, these unmet psychosocial needs have not been systematically reviewed.

### *Objectives and the research questions*

The primary objective of this scoping review was to determine the categories of unmet psychosocial needs of young women with breast cancer and the extent to which these needs had been studied in past studies. The secondary objective of this review was to explore the effects of unmet psychosocial needs on the quality of life of young women with breast cancer. The research questions that guided this review were:

1. What are the unmet psychosocial needs of young

Faculty of Medicine and Health Sciences, Universiti Malaysia Sarawak, 94300 Kota Samarahan, Sarawak, Malaysia.

\*For Correspondence: kschev@unimas.my

women with breast cancer?

2. What are the effects of unmet psychosocial needs on the quality of life of young women with breast cancer?

## Materials and Methods

### Procedures

The procedure used in this scoping review followed the five-step framework outlined by Arksey and O'Malley [14]. The steps in this framework are: (1) defining the research objectives or questions; (2) identifying relevant studies; (3) selecting studies for inclusion based on predefined inclusion and exclusion criteria; (4) tabulating and interpreting the data; and (5) collating, summarizing, synthesizing, and reporting the results. The protocol of this scoping review was registered through the Medical Ethics Committee of the Universiti Malaysia Sarawak (No. FME/22/42).

### Search strategy

The search strategy was conducted using the methodology described by Aromataris and Riitano [15]. Five electronic databases (MEDLINE from the National Library of Medicine, Cumulative Index of Nursing and Allied Health Literature (CINAHL), SCOPUS, Web of Science WOS, and Google Scholar), as well as reference lists of relevant literature were systematically searched to identify the relevant literature following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for reporting systematic reviews [16]. Only articles published since the year 2004 were chosen. This period was chosen because it was a starting point to understand that young women's needs and concerns are unique and more age-specific. A qualitative study explored young and older women's needs and found that the accessed information and services for breast cancer women did not fit or match young women's age and life stages [17]. In the articles that include young and old breast cancer women, only the results related to young women were reported.

The literature search was conducted using the following keywords and Boolean operators either individually or in combination: breast cancer, breast neoplasm\*, premenopausal, young women, young woman, psychosocial need\*, psychosocial issue\*, psychosocial concern\*, psychological distress\*, psychological need\*, social need\*, emotional need\*, information needs\*, spiritual need\*, practical need\*, supportive care need\*, unmet supportive need\*, and quality of life\*.

### Eligibility criteria

#### Participants Criteria

Breast cancer women 50 years old or younger or pre-menopausal at the time of diagnosis with a first-time diagnosis of breast cancer were the criteria to define as participants. In fact, there is no consensus on the definition of young women in the literature. Some studies defined young women as those 40 years old or younger [13], and others as those 50 years old or younger [4, 3].

### Studies criteria

#### Inclusion criteria

(1)- Peer-reviewed original full-text research articles qualitative or quantitative published in the English language only

(2)- Involving female patients (only) aged 50 years or younger with a first-time diagnosis of breast cancer.

#### Exclusion criteria

(1)- Articles such as anecdotal reports, testimonies, stories published in trade or popular magazines, and other grey literature were excluded.

(2)- Literature review articles as well as studies that included breast cancer patients together with different types of cancer were also excluded.

(3)- Studies focusing solely on the quality of life of young women with breast cancer were also excluded.

#### Study selection and data extraction

Both authors screened for articles independently for eligibility to be included in this review. The screening was initially on the title and the abstract of each article. If the article was relevant to the review, then the entire article was reviewed and checked for meeting the eligible criteria. If there was any disagreement between the authors, discussions were held together with a third independent reviewer to resolve the dispute through consensus.

## Results

### Literature search

A total of 2505 records were retrieved. After excluding 1479 duplicates, a total of 1026 studies were retrieved for titles and abstract screening. After screening titles and abstracts, 913 articles were excluded and 108 papers were retrieved for full-text review. The final 30 articles, which consisted of 22 qualitative, and 8 quantitative studies were included. The PRISMA flow chart of the literature search is shown in Figure 1.

### Literature characteristics

The final 30 articles included 22 qualitative and 8 quantitative studies. The literature characteristics are summarized in Table 1. As shown in Table 1, the articles were published from 2004- 2023. Eleven studies were published in the period from 2014-2018. Most qualitative studies used In-depth, semi-structured interviews for data collection. Three quantitative studies used the Supportive Care Needs Survey to collect the data. These reviewed studies found that young women have distinct perceived needs compared to their older counterparts, with more age-specific concerns related to fertility, body image, menopause, sexuality, career, and family. Table 2 illustrates how these needs can be categorized into 13 main domains: information needs, psychological needs, physical/symptoms needs, fear of recurrence and spreading, identity-related needs, social needs, sexual needs, social support, financial support, practical needs, spiritual needs, communication-related issues with health care providers, and coping needs. Data were extracted and summarized in a narrative synthesis. The supplementary

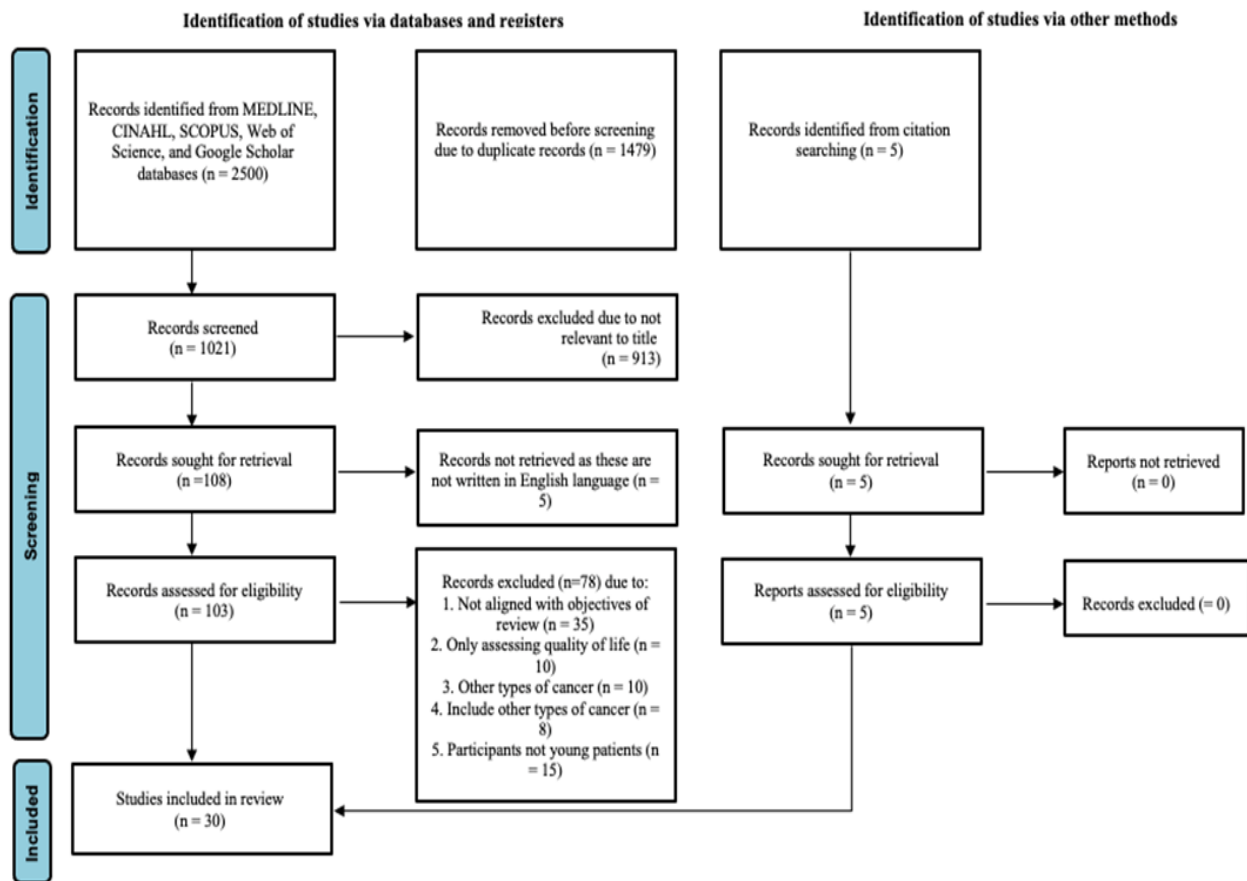


Figure 1. PRISMA Diagram of Literature Search Process

Table shows the details of the extracted data from the studies.

#### Studies quality assessment

Each included study was assessed for the methodological quality by the first author following Joanna Briggs Institute (JBI) critical appraisal checklist [42]. The overall risk of bias was low to moderate for both the qualitative and quantitative studies. In the qualitative studies, 36.4% had ‘Yes’ responses to all nine items and 31.8% had ‘Yes’ responses to 8 items. In the quantitative studies, 50% had ‘Yes’ responses to all nine items addressed in the checklist.

#### Unmet Informational Needs

The category of unmet informational needs was identified in 14 of the 30 reviewed studies. The highest unmet information needs were related to age information needs, information about the disease and the treatment plans, and information about medication and side effects of fertility, premature menopause, and sexuality. The reviewed studies revealed that women’s information needs were fluid and changed according to cancer stage, time since diagnosis, age, and marital status [31, 37]. This dissatisfaction with the received information has been shown to impact illness perception negatively and the patient’s quality of life, while higher satisfaction with information was shown to correlate with better health outcomes and psychological well-being [9, 31, 27]. Lack

of information was found to increase uncertainty, distress, anxiety, and fear, and could negatively influence treatment decision [13].

#### Unmet Psychological Needs

As shown in Table 2, Psychological needs were identified as the highest unmet need category in young women with breast cancer as addressed in 21 studies. The highest unmet information needs were related to concerns about fertility and premature menopause as reported in 14 studies, followed by uncertainty about cancer and treatment, and future as reported in 10 studies. Young breast cancer women were very uncertain regarding their fertility, reproduction, and parenting describing that this was very traumatic for them specifically for those who hope to have children [34, 36]. Some women mentioned that they were given the choice to preserve their eggs to have options in the future, however, such a procedure was expensive, costing around \$8000, which was a significant obstacle for them to do so. Communication issues with healthcare providers were also identified as a cause of unmet psychological needs [9, 13] and it was recognized as the most unmet related to the quality of life of young breast cancer patients.

#### Fear of recurrence and spreading

Fear of recurrence or spreading of breast cancer was also reported as a frequent unmet need among young breast cancer women to the extent that this fear led to functional

Table 1. Literature Characteristics

Study Characteristics	Count (%)	References
<b>Publication Year</b>		
2004-2008	6	[17-22]
2009-2013	6	[23-25, 12, 26, 27]
2014-2018	11	[28, 29, 9, 2, 30, 31, 10, 32-35]
2019-2023	7	[13, 36-41]
<b>Types of studies</b>		
Qualitative	22	[2, 10, 13, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 29, 30, 32, 34, 35, 36, 39, 40, 41]
Quantitative	8	[9, 12, 27, 28, 31, 33, 37, 38]
<b>Country of origin</b>		
United States	5	[20, 26, 30, 41, 34]
Canada	3	[21, 32, 22]
Australia	7	[17, 10, 18, 12, 19, 23, 38]
Mexico	3	[35, 13, 33]
Syria	2	[25, 40]
Lebanon	1	[31]
Oman	1	[29]
Taiwan	1	[37]
Iran	1	[28]
Ireland	1	[36]
Indonesia	1	[27]
Japan	1	[9]
Brazil	1	[2]
Turkey	1	[24]
Nigeria	1	[39]

impairment, psychological symptoms, poor quality of life, and excessive efforts to control or avoid any sign of cancer recurrence. Young women were not only scared of the recurrence, but they also were afraid of death and leaving their children motherless. They also were worried about passing on cancer to their daughters or children in the future. Fear of cancer recurrence was also associated with higher rates of depression and anxiety [12].

*Identity needs*

Identity needs also appeared as an unmet need category in the reviewed studies and were identified in 16 studies. The highest unmet need in this category was related to a sense of loss of femininity due to impaired body image. The reviewed studies showed that young breast cancer women experience a sense of shifting identity due to losing their hair and breasts to the extent they cannot recognize themselves when they look in the mirror which makes them more emotionally affected and depressed [34, 36, 40].

*Unmet Practical Needs*

The category of unmet practical needs was identified as

Table 2. Prominent Needs Lists of Each Domain

Category	List of needs	References
Information needs	Age information needs	[21, 32, 13, 35, 22, 17, 37, 27]
	Information about the disease and the treatment plans	[13, 21, 32, 24, 22, 17, 37, 27]
	Information about medication and side effects of fertility, premature menopause, and sexuality	[9, 13, 18, 24, 25, 26, 24, 30]
	Advice on what services and help are available	[13, 22, 26, 35]
	Information about diet, exercise, permitted daily activities, and alternative therapies.	[9, 13, 17, 22, 26, 35, 37]
	Information for the children, partners, family	[13, 22, 26]
	Access to support and community services	[22, 26, 30, 32]
	Information about what to expect in survivorship	[26]
	Written and audiovisual sources	[13]
	Information is given sensitively	[13]
Psychological needs	A Sense of guilt for not meeting the children's and partners' needs	[21, 26, 40, 41]
	Uncertainty about cancer and treatment, and future	[2, 19, 21, 26, 29, 31, 32, 35, 36, 41]
	Angry, frustrated, and a sense of being out of control	[2, 21, 23]
	Anxiety	[13, 21, 24, 26, 35, 36, 38]
	Depression	[2, 21, 25]
	Emotional Distress	[13, 25, 26, 29, 32, 35, 40]
	Inadequate psychological support	[13, 22, 25, 26, 29, 32, 35, 4]
	Cognitive difficulties	[21]
	Concerns about fertility and premature menopause	[9, 13, 17, 18, 19, 20, 21, 23, 24, 26, 34, 35, 36, 41]
	Symptom management needs (pain, nausea, vomiting, wound management, fatigue)	[13, 25, 26]
Physical/symptom	Coping with treatment side-effects	[23, 30, 39]
	Fear of recurrence and spreading	Fear of recurrence and spreading
Fear of mortality and leaving the children motherless		[2, 10, 19, 24, 26, 29]
Fear for daughters/children would get BC		[23, 26, 29, 35, 36, 39, 41]
Identity needs	Fear of chemotherapy	[2, 10, 29]
	Sense of loss of femininity due to impaired body image	[13, 19, 21, 23, 24, 25, 39, 40, 41]
	Loss of sense of self of who I am	[2, 20, 34, 35, 36, 40]
Social needs	Feeling out of sync due to the side effects of treatment.	[21, 22, 24, 26, 35, 40, 41]
	Referral networks	[17, 21]
	Feeling stigmatized	[2, 25, 29, 35, 40]
	Sense of isolation from others	[2, 17, 21, 25, 29, 32, 35, 39, 41]
	impaired roles and responsibilities as mothers and wives	[2, 19, 21, 25, 29, 41]

Table 2. Continued

Category	List of needs	References
Social needs	lack of marriage choices	[22, 25, 26, 35, 40]
	Change society's view of breast cancer patients	[25, 40]
Sexual needs	impact of treatment / restriction / alteration in a sexual relationship and intimacy	[13, 17, 19, 20, 21, 22, 25, 26, 32, 33, 35, 39, 40]
	support from the Family	[16, 17, 21, 22, 23, 26, 31]
	support Health professionals	[16, 17, 21, 22, 26]
Social support	support from friends	[21, 22, 26, 31]
	supportive work environments	[13, 18, 26]
	Peer emotional support	[17, 19, 26, 38]
	Appropriate support for their family and partners	[13, 17, 19, 22]
Practical	Professional counselling	[17]
	Difficulties in balancing the needs of the family	[21, 22, 23, 29]
	Difficulties in maintaining their physical/daily lives, careers or work, and education	[2, 17, 21, 22, 23, 26, 29, 30, 33, 34, 35, 41]
	Difficulties in performing household chores	[19, 22, 32, 35]
	Child care needs	[19, 21, 22, 23, 32, 35]
Financial support	Financial burden/ cost of care	[19, 41]
	Cost of the reconstruction procedure	[40]
	Cost of fertility preservation	[34]
	Dealing with insurance issues and work leave aspects	[19, 22, 26]
Spiritual needs	Help with my spiritual beliefs	[22]
Communication-related issues with healthcare providers	Inadequate communication with healthcare providers	[9, 13]
	Communication strategies with the medical team	[9, 13]
Coping	Difficulty coping	[19, 22, 23]

unmet in 13 studies. The highest unmet need was related to difficulty maintaining their physical/daily lives, careers or work, and education. Specifically, it was found that these young women often faced unmet family and childcare needs such as the struggle to juggle their roles as wives and mothers as well as the dissatisfaction with the childcare

services in the cancer care facilities.

### Unmet Social Needs

The category of unmet social needs of young women with breast cancer was identified in 14 of the 30 studies. These studies revealed that young women often had to withdraw from society and experienced social isolation after their diagnosis, due to changes in physical appearance from treatments like hair loss, weight changes, and breast loss [29, 40, 25] or to avoid societal pity. Young women also felt separated and isolated from the support groups that did not fit their ages.

### Unmet Sexual Needs

The category of unmet social needs of young women with breast cancer was identified in 13 of the 30 studies. This is mostly related to women's perception of themselves as half-woman with only one breast and they are no longer attractive to their partners, so, they avoid sexual relationships [40].

### Social support

Social support also appeared as unmet to young breast cancer women specifically during the transition to survivorship due to reduced support from partners, family, friends, and health professionals. The women not only wanted support for themselves but also for their partners and family who became very emotionally distressed after their wives got breast cancer [17, 19, 22].

### Financial support

Financial support also appeared as unmet to young breast cancer women in some of the reviewed studies with lower income and higher financial stress are linked to more psychosocial needs and a lower quality of life [22, 35, 40].

## Discussion

This scoping review identified the categories of significant unmet psychosocial needs of young women with breast cancer and their impact on quality of life. The most commonly identified unmet needs were psychological, with 21 out of 30 studies addressing this category. This is because younger women, still in the process of establishing their lives and pursuing goals,

Table 3. Mapping of Factors of Unmet Psychological Needs Using the Biopsychosocial Model

(Treatment-Related Impacts)	(Life Stage-Related Challenges)	(Support System Deficiencies)	(Socio-Cultural Factors)
Fear of recurrence [9, 10, 12, 13, 21, 29, 36, 39]	Reduced support during the transition to survivorship [31, 28, 24]	Communication issues with healthcare providers [9, 13]	Stigmatization and social isolation [2, 25, 29, 35, 40]
Body image and sexuality [13, 19, 21, 23, 24, 25, 39, 40, 41]	Balancing career, children, and relationships [21, 22, 23, 29]	Support diminishment	Stigmatization in some cultures [25, 40]
	The emotional impact of losing breasts and femininity [40, 41, 24]	From partners, family, and friends [16, 17, 21, 22, 23, 26, 31]	
	Disruption of life plans and future aspirations [2, 17, 21, 22, 23, 26, 29, 30]		



face severe disruption from a breast cancer diagnosis and aggressive treatments such as mastectomy and chemotherapy [43, 21]. The treatment-related side effects, including altered body image, sexual dysfunction, premature menopause, infertility, and weight changes, exacerbate these psychological needs [2, 35].

Numerous factors have been shown to have contributed to this high level of unmet psychological needs. Interestingly, it was found that these factors can be broadly mapped using the biopsychosocial model [44]. Biological factors include treatment-related impacts such as fear of recurrence and body image issues. Psychological factors include life stage-related challenges such as disrupted life plans, balancing career and family, and future uncertainty, leading to increased anxiety and depression, as well as the emotional distress of losing breasts and femininity as a result of the aggressive treatments. Social factors, which can be further divided into either (1) support system deficiencies, and (2) socio-cultural influences, include factors such as reduced support from partners and family, ineffective communication with healthcare providers, and cultural stigma that leads to social withdrawal and isolation. The mapping of these factors using the biopsychosocial model is shown in Table 3.

Financial concerns were identified as a frequent unmet practical need. The treatment's high costs, estimated at around USD 895 billion globally or more, can lead to significant financial strain, particularly for young women who face employment disruptions [35, 7]. In fact, these financial burdens can affect not only the patients but their families as well [4, 45-47]. As mentioned, social concerns in this study were also prominent, with young women reporting societal stigma towards breast cancer. This stigma can lead to feelings of unattractiveness and social isolation [29, 25]. Spiritual needs were noted as unmet to some extent. Spirituality plays a vital role in enhancing optimism, strength, and peace of mind, helping women overcome obstacles and continue their lives with a sense of forgiveness and closeness to God [2, 40].

#### *Limitations of the study*

To the best of our knowledge, this study is the first and most comprehensive systematic scoping review regarding the psychosocial needs of young women with breast cancer. However, this scoping review is subject to several limitations. The majority of included studies were qualitative studies, with very few studies assessing the unmet psychosocial needs of young breast cancer women, which might affect the generalisability of the data. We did not include articles that are categorised as grey literature or other forms of nonpeer review articles, which might have resulted in biased outcomes. The first author assessed the quality of studies, which may result in some bias. The data obtained from this scoping review necessitates addressing the psychosocial needs of young women with breast cancer quantitatively using validated instruments.

In conclusion, the insights identified from this scoping review reveal the multifaceted nature of unmet psychosocial needs among young women with breast cancer, highlighting the necessity for comprehensive,

holistic care approaches to address these various dimensions. Specifically, the relationship between the unmet psychosocial needs and the quality of life of young breast cancer women should be clearly understood by healthcare providers to render a strong support system that can improve the quality of life of these young women with breast cancer.

#### **Author Contribution Statement**

Both authors had contributed to this study. Shaza Hasan designed the original study protocol. Shaza Hasan and Keng Sheng Chew conducted literature searches and screenings. Shaza Hasan has assessed the quality of the included studies. Shaza Hasan and Keng Sheng Chew performed the data analysis. Shaza contributed to writing the manuscript, and Keng Sheng Chew reviewed the manuscript.

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##### *Availability of data and materials*

All data generated or analysed during this study are included in this article.

##### *Declarations*

Ethics approval and consent to participate

This study is a scoping review did not require ethical approval or consent to participate. However, as it is a part of Ph.D thesis, it was approved by the medical ethics committee of the Universiti Malaysia Sarawak (No. FME/22/42).

##### *Conflict of Interest*

The authors declare that there are no conflicts of interest concerning the content of the present study.

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