REVIEW ARTICLE

A Systematic Review of Health-Related Quality of Life Assessment Instruments for Cancer Patients: A Malaysian Perspective

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ABSTRACT

Introduction	The absence of a review of health-related quality of life (HRQoL) assessment tools has led to inconsistencies in the use of HRQoL instruments across different cancer populations, such as adults, pediatric patients, and caregivers, limiting the comparability of findings and hindering the accurate evaluation of cancer care outcomes. With that, this study aimed to investigate how Malaysian cancer patients' and other sub-population's HRQoL is measured and quantified through HRQoL assessment instrument.
Methods	From 2013 to 2023, a literature search was conducted on Scopus, PubMed, Cochrane Library, and ClinicalTrials.gov. The included studies and previously published review papers were also cited backward. For each HRQoL assessment instrument, attributes such as author(s), year of publication, study site, study design, target population, cancer types, study purpose, sample size, and instrument languages were extracted and compared.
Results	In this systematic review encompassing 88 studies, a variety of HRQoL assessment tools were employed, including both generic and cancer-type specific instruments. Distinct HRQoL assessment tools were identified for different populations, including pediatric, adolescent, and caregiver groups. The findings underscore the wide variety of instruments used across different cancer populations and age groups, highlighting the need for tailored assessments that consider specific demographic and clinical contexts. While generic HRQoL tools were the most commonly used across studies, disease-specific instruments for various cancer types were also frequently employed as supplementary measures.
Conclusion	Moving forward, it is essential for stakeholders to collaborate in addressing the gaps in HRQoL research and to work towards the standardization of HRQoL assessment tools to ensure consistency and comparability in future studies.
Keywords	Health-Related Quality of Life, Neoplasms, Malaysia, Assessment, Review

Article history
Received: 18 September 2024
Accepted: 21 February 2025
Published: 10 March 2025

INTRODUCTION

Cancer remains a persistent health challenge in Malaysia, as evidenced by its enduring status as a leading cause of mortality, as indicated in the 2023 Malaysia Health White Paper. With an estimated 48,639 new cancer cases diagnosed annually, the burden of this disease continues to grow, affecting individuals and families across all socioeconomic strata.[1] The increasing prevalence of cancer imposes a dual impact on society: a direct economic burden through rising healthcare costs and an indirect impact due to loss of productivity. The mean total out-of-pocket cost of cancer was estimated at MYR 7,955.39 (US$ 1,893.46) per patient per year, with direct non-medical costs being the largest contributor, accounting for 46.1% of the total cost. These costs were primarily driven by expenditures on supplemental food and transportation. Indirect costs, resulting from lost productivity and caregiving responsibilities, contributed 36.0% of the total cost, while direct medical costs accounted for 17.9%.[2] The increasing prevalence of cancer not only imposes a substantial financial burden due to escalating healthcare costs but also substantially affects the nation's economic productivity. Non-communicable diseases, notably cancer, have been attributed to a discernible loss in the country's Gross Domestic Product (GDP), estimated at approximately 1%, primarily stemming from reduced productivity.[3]

Malaysia operates a dichotomous healthcare system, consisting of public and private sectors, each catering to different segments of the population. The public healthcare system, heavily subsidized by the government, is the primary source of care for most Malaysians, particularly those from lower- and middle-income groups. However, it faces challenges such as resource constraints, long waiting times, and increasing demand. On the other hand, the private healthcare sector offers faster access to medical services and advanced treatments but at a significantly higher cost, making it unaffordable for many individuals. This dual system places considerable financial strain on patients, especially those requiring long-term treatments like cancer care, which often compels them to deplete savings or seek financial support from family and friends. Recognizing this challenge, the government aims to pivot its approach from solely considering the monetary value of medications to embracing a value-based healthcare model. This approach emphasizes equitable, accessible, and resilient healthcare systems, reflecting the populace's values and ensuring continuous system enhancement.[4, 5]

Health technology assessment (HTA) is widely employed to evaluate the integration and diffusion of novel medical technologies, including pharmaceuticals, medical devices and services, and diagnostic tools, within healthcare systems globally. This interdisciplinary approach is instrumental in guiding healthcare decisions and policy-making endeavours, particularly within value-based models. Recent years have witnessed a notable shift towards developing frameworks aimed at streamlining the value assessment process in HTA, departing from traditional "fee-for-service" approaches. These frameworks are meticulously designed to facilitate value assessment initiatives and enhance decision-making pertaining to the implementation or coverage of emerging technologies in healthcare settings.[6, 7] In the context of Malaysia's value-based healthcare system, significant preliminary groundwork and time investment are necessary to establish a national value-assessment framework. Moreover, substantial resources and manpower are required to develop disease-specific value assessment frameworks. In light of this, there is a growing national consensus advocating for local researchers to align their research directions towards conducting policy research to support future policy development initiatives.[8, 9]

The ISPOR Value Flower, a widely recognized framework, highlights Health-Related Quality of Life (HRQoL) as a vital component of healthcare value, underscoring its role in capturing patient-centered outcomes, including physical, psychological, and social well-being.[10] HRQoL assessment, therefore, contributes not only to HTA but also to the development of value-based healthcare frameworks by providing a holistic perspective on the impact of diseases and treatments on patients' physical, emotional, and social well-being. HRQoL encompasses various dimensions, including physical functioning, psychological well-being, social relationships, and overall life satisfaction.[11, 12] It serves as a holistic measure of an individual's health status and provides valuable information for healthcare decision-making and policy development.

However, cancer exhibits heterogeneity, with symptoms, treatments, and side effects varying according to the type and stage of the disease. Moreover, Malaysia comprises multiple ethnicities, including Malay, Chinese, Indian, and indigenous populations, each with distinct genetic profiles, further complicating the presentation of cancer.[13] Besides, caregivers often experience significant emotional, physical, and financial burdens due to their caregiving responsibilities. Their well-being is closely intertwined with that of the patient, and their quality of life can be severely impacted by the demands of providing care. This complexity further complicates HRQoL assessment, as current research often focuses on a limited set of assessment tools, with many researchers being unaware of disease-specific or sub-population-specific instruments that could provide more nuanced and meaningful evaluations. Consequently, this gap in knowledge has led to inconsistencies in the use of HRQoL instruments across different cancer populations,

such as adults, pediatric patients, and caregivers, limiting the comparability of findings and hindering the accurate evaluation of cancer care outcomes.

It is therefore essential for researchers and government entities to identify suitable tools for assessing the quality of life of Malaysian cancer patients. To our knowledge, there has been no comprehensive review on HRQoL assessment instruments that has been used in Malaysia for different types of cancer. This review was motivated by the growing national interest in expanding the incorporation of patients' perspective in assessing value of health technologies. Therefore, this paper aims to focuses on HRQoL assessment instruments that have been used on Malaysian cancer patients.

METHODS

A systematic literature review was conducted on studies looking at Malaysian population-based HRQoL surveys involving cancer patients and their caregivers. The review followed the recommendations contained in the Preferred reporting items for systematic review and meta-analyses protocols (PRISMA-P) statement.[14]

Search Strategy

A systematic literature searches of journal articles published from 2013 to 2023 was conducted on several databases including Scopus, PubMed, Cochrane Library and ClinicalTrials.gov. Search terms included "value," "value-based," "quality of life," "HRQoL," "quality-adjusted life years," "indirect cost," "cancer," "neoplasm" and "assessment." Detailed search strategies are presented in Supplementary Material 1. The searches were performed during the period October 2023 to January 2024 and were limited to articles published between January 2013 and December 2023 in English language only. In terms of full-text review and systematic reviews, backward citation chaining was conducted to identify further relevant literature.

Study selection

A two-stage screening, which consisted of the initial title and abstract screening and subsequent full-text review was conducted by researcher 1 using the predesigned screening forms. The full texts of potentially eligible articles after the title and abstract screening were retrieved and reviewed. Any disagreement between reviewers during the screening was discussed and resolved through group discussion.

For this review, articles were included if they satisfied all of the following criteria: the study population was Malaysian, the study population consisted of cancer patients or their caregivers, and the study outcome included HRQoL quantified using a specific, validated quantitative assessment instrument. Articles were excluded if they did not meet these requirements or if they focused on non-Malaysian populations (including multinational sample without stratified results specific to Malaysians), involvement of individuals with medical conditions other than cancer, or primarily evaluated, adapted, or validated existing HRQoL assessment instruments without reporting HRQoL outcomes. Furthermore, articles such as protocols, clinical practice guidelines, policy papers, commentaries, or opinion pieces that did not involve primary research or original HRQoL data were also excluded. In cases where multiple publications reported on the same HRQoL assessment instrument, all relevant publications were included to ensure comprehensive coverage of the tool's applications.

Data Extraction and Synthesis

The data extraction was conducted by researcher 1 and any discrepancy was resolved through group discussions. Prior to the data extraction, researcher 2 and 3 had designed the screening and data extraction form together with researcher 1 and provide necessary training to researcher 1. For each HRQoL assessment instrument included in the study, information such as author(s), year of publication, study site, study design, target population, cancer types, study purpose, sample size, HRQoL assessment instruments used and languages of HRQoL assessment instruments used. The principle of non-overlapping was followed through the extraction categorisation process by cross-checking the author(s) and sample size within each category to avoid double counting.

RESULTS

Study Characteristics

Figure 1 presents a total of 34,802 records identified in the database searches. Following the removal of 1,235 duplicates, the titles and abstracts of 32,487 literature pieces underwent screening. Subsequently, 1,225 literatures were shortlisted for full-text screening, during which inclusion and exclusion criteria were evaluated. Out of the 1,225 literatures, 1,136 papers were excluded for various reasons: 455 due to the absence of HRQoL assessment instruments, 334 studies not conducted in Malaysia, 172 papers categorised as abstracts, validation studies, protocols, clinical practice guidelines, policy papers, comments, or opinions about HRQoL assessment instruments, 81 multicentre studies involving countries other than Malaysia, 49 reviews with backward citation chaining earlier than 2013, and 45 not related to cancer. Finally, 88 literatures were included in the review.

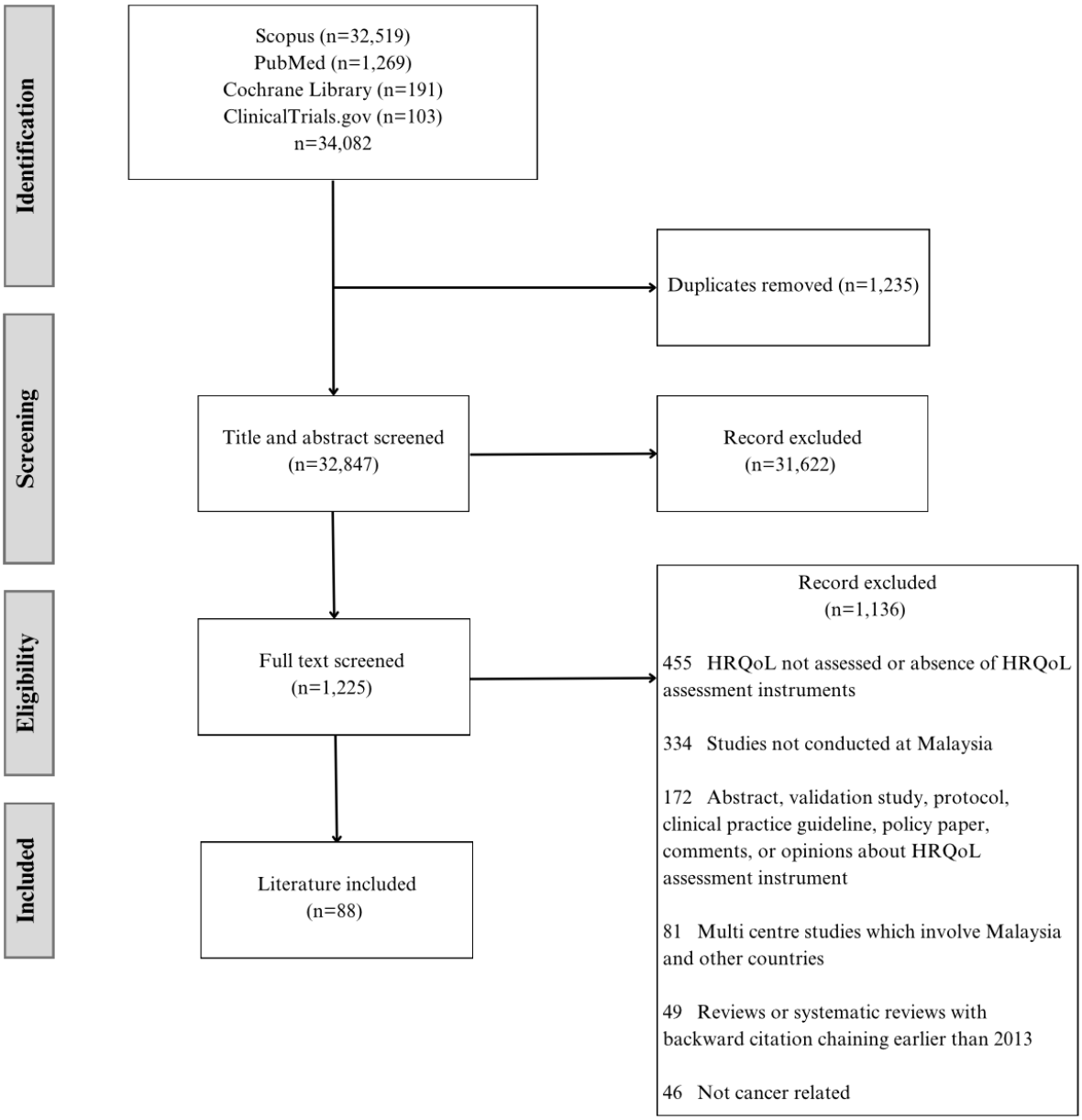

Figure 1 Schematic illustration of the literature screening flow

Supplementary Material 2_Table 1 delineates the characteristics of the studies encompassed within the review, totalling 88 in number. The examination of study designs reveals a dominant prevalence of cross-sectional studies, comprising 57 studies (64.8%), followed by experimental or interventional clinical trials constituting 16 studies (18.2%) and cohort, prospective, or longitudinal studies accounting for 15 studies (17.0%) of the total. In terms of study populations, the vast majority of investigations concentrated on adult cancer patients, representing 79 studies (89.8%). A smaller proportion of studies involved cancer patients' caregivers (4 studies, 4.5%), adolescent cancer patients (2 studies, 2.3%), a combination of cancer patients and caregivers (2 studies, 2.3%) and paediatric cancer patients (1 study, 1.1%).

In terms of the distribution of cancer types, as shown in Table 1, breast cancer emerged as the most prevalent focus, accounting for 32 studies (36.4%), followed by general cancer types, encompassing 22 studies (25%) of the total. In this review, general cancers indicate such study includes more than one type of cancer. Blood-related cancers constituted 10 studies (11.4%), while head and neck cancers was studied in 8 studies (9.1%). Colorectal cancer investigations represented by 6 studies (6.8%), whereas studies focusing on gastric or gastroesophageal cancers and gynaecological cancers each comprised 3 studies (3.4%). A minority of studies examined prostate cancer (2 studies,

2.3%), brain cancer (1 study, 1.1%) and orthopaedic cancers (1 study, 1.1%).

Supplementary Material 2_Table 2 provides a comprehensive overview of the study population sizes across various cancer types, comprising a total of 20,066 Malaysian cancer patients. The data is presented both in absolute numbers and as a percentage of the total study population. The largest study population size is observed among individuals with general cancer, constituting 10,815 individuals, which represents 53.9% of the total study population. Following closely behind, individuals diagnosed with breast cancer comprise 4,676 study subjects, accounting for 23.3% of the total study population. Blood-related cancers encompass a study population size of 1,461 individuals, representing 7.3% of the total. In contrast, certain cancer types exhibit smaller study populations. For instance, colorectal cancer and head and neck cancer each account for 883 patients (4.4%) and 869 patients (4.3%), respectively. Gastric or gastroesophageal cancer and gynaecological cancer are represented by 442 individuals (2.2%) and 360 individuals (1.8%), respectively. Further delineating the distribution, orthopaedic cancer and prostate cancer demonstrate study populations of 191 subjects (1.0%) and 331 subjects (1.6%), respectively. Lastly, brain cancer is least represented by 38 individuals, constituting 0.2% of the total study population.

HRQoL Assessment Instruments for Adult Cancer Patient Population

Twenty different HRQoL assessment instruments were used in the studies on adult cancer patients (n=81), 8 of which is generic and 12 specific instruments. Despite the varied utilization patterns of HRQoL assessment instruments across different cancer types, the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30) emerges as the most widely utilized instrument across various cancer types, with 38 instances of its usage identified in the literature. Following closely behind, the World Health Organization Quality-of-Life Scale (WHOQOL-BREF) is prominently employed in 11 literatures, indicating its relevance and applicability in assessing HRQoL among cancer patients. Moreover, the European Organization for Research and Treatment of Cancer Quality of Life Questionnaires – Breast Module (EORTC QLQ-BR23) and Functional Assessment of Cancer Therapy-Breast (FACT-B) instruments are utilized in 9 and 7 studies, respectively, emphasizing their significance in evaluating specific aspects of HRQoL, particularly in breast cancer patients. Additionally, the EuroQol-5 Dimensions-5 Levels (EQ-5D-5L) instrument is employed in 6 literatures, underscoring its utility in capturing diverse dimensions of HRQoL across different cancer populations. The HRQoL assessment instruments used to evaluate various types of cancer are delineated in Table 1.

Table 1 HRQoL assessment instruments for cancer patient (adult)

HRQoL assessment instrument for cancer patient (adult)	n (%)	References
General		
EORTC QLQ-C30	9(47.4)	Lee & Zakaria;[15] Farooqui et al;[16] Zainordin et al;[17] Subramaniam et al;[18] Rosli et al;[19] Zainordin et al;[20] Ali et al;[21] Loke et al;[22] Marzo et l[23]
WHOQOL-BREF	6(31.6)	Periasamy et al;[11] Naing et al;[24] Akhtari-Zavare et al;[25] Periasamy et al;[26] Subramaniam et al;[27] Sivaperumal et al[28]
FACT-G7	2(10.6)	Ting et al;[29] Ting et al[30]
EQ-5D-5L	1(5.3)	Subramaniam[18]
FACIT-F40	1(5.3)	UNIMAS[31]
SF-36	1(5.3)	Sharifa Ezat et al[32]
Breast		
EORTC QLQ-C30	15(46.9)	Lua et al;[33] Liew et al;[34] Dang et al;[35] Lua et al;[36] Edib et al;[37] Ng et al;[38] Syed Alwi et al;[39] Ganesh et al;[40] Sham et al;[41] Chui et al;[42] Nurnazahiah et al;[43] Yusuf et al;[44] Dahlui et al;[45] Law et al;[46] Ng et al[47]
EORTC QLQ-BR23	9(28.1)	Lua et al;[36] Ganesh et al;[40] Sham et al;[41] Chui et al;[42] Nurnazahiah et al;[43] Yusuf et al;[44] Dahlui et al;[45] Law et al;[46] Ng et al[47]

	FACT-B	7(21.9)	Sharif & Khanekharab;[48] Rufa'i et al;[49] Pahlevan;[50] Rufa'i et al;[51] Loh et al;[52] Ahadzadeh & Sharif;[53] Abu Kassim et al[54]
	WHOQOL-BREF	3(9.4)	Poo;[55] Dominic et al;[56] Ramadas et al[57]
	16-item MQOL	2(6.3)	Pahlevan Sharif & Ong;[58] Pahlevan Sharif et al[59]
	Breast Cancer QoL Instrument adopted from City of Hope	1(3.1)	Zubaidah[60]
	EQ-5D-5L	1(3.1)	Yusoff[61]
	FACIT-F40	1(3.1)	Muthanna[62]
	FACT-G7	1(3.1)	Kassim et al[54]
	Menopause rating scale	1(3.1)	Choo et al[63]
	SF-36	1(3.1)	Loh et al[64]
Blood			
	EORTC QLQ-C30	4(50.0)	Tan et al;[65] Gan et al;[66] Ng et al;[67] Gan et al[68]
	EORTC QLQ-CML24	2(25.0)	Tan et al;[65] Gan et al;[66] Ng et al;[67] Gan et al;[68] Kuan[69]
	EQ-5D-5L	2(25.0)	Wan Puteh;[12] Wan Puteh[70]
	EQ-5D-5L (VAS)	1(12.5)	Wan Puteh[12]
	WHOQOL-BREF	1(12.5)	Razali & Sulaiman[71]
Brain			
	EORTC QLQ-C30	1 (100.0)	Ooi & Mazlan[72]
	EORTC QLQ-BN20	1 (100.0)	Ooi & Mazlan[72]
Colorectal			
	EORTC QLQ-C30	5(83.3)	Wan Puteh et al;[73] Abu Zaid;[74] Wan Puteh;[75] Golkhalkhali;[76] Loh et al[77]
	SF-12	1(16.4)	Abdullah[78]
Gastric or gastroesophageal			
	EORTC QLQ-C30	2 (100.0)	Tata et al;[79] Chuah et al[80]
	EORTC QLQ-OG25	1(50.0)	Tata et al[79]
Gynaecological			
	EORTC QLQ-C30	2 (66.6)	Mohammad et al;[81] Azmawati et al[82]
	EORTC QLQ-CX24	1 (33.3)	Azmawati et al[82]
	EQ-5D-5L	1 (33.3)	Hasan et al[83]
	EQ-5D-5L (VAS)	1 (33.3)	Hasan et al[83]
	SF-36	1 (33.3)	Hasan et al[83]
Head and neck			
	FACT-H&N	4 (57.1)	Aminnudin et al;[84] Ramasamy et al;[85] Doss et al;[86] Doss et al[87]
	FACT-H&N-MAQ	2 (28.6)	Doss et al;[86] Doss et al[87]
	EORTC QLQ-H&N35	1 (14.3)	Hamdan et al[88]
	EQ-5D-5L	1 (14.3)	Rahman et al[89]
	EQ-5D-5L (VAS)	1 (14.3)	Rahman et al[89]
	Head and neck cancer specific quality of life questionnaire	1 (14.3)	Lim et al[90]
Orthopaedic			
	WHOQOL-BREF	1 (100.0)	Ungar[91]
Prostate			
	SF-36	2 (100.0)	Isa et al;[92] Isa et al[93]

Abbreviation: EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30; WHOQOL-BREF, World Health Organization Quality-of-Life Scale; FACT-G7, Functional Assessment of Cancer Therapy-General; EQ-5D-5L, EuroQol-5 Dimensions-5 Levels Questionnaire; FACIT-F40, Functional Assessment of Chronic Illness Therapy-Fatigue; SF-36, 36-Item Short Form Survey; EORTC QLQ-BR23, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Breast Module; FACT-B, Functional Assessment of Cancer Therapy-Breast; MQOL, McGill Quality of Life Questionnaire; EORTC QLQ-CML24, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Chronic Myeloid Leukaemia Module; EQ-5D-5L (VAS), EuroQol-5

Dimensions-5 Levels-Visual Analogue Scale; EORTC QLQ-BN20, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Brain Module; SF-12, 12-Item Short Form Survey; EORTC QLQ-OG25, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Oesophago-Gastric Module; EORTC QLQ-CX24, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Cervical Module; FACT-H&N, Functional Assessment of Cancer Therapy-Head and Neck Scale; FACT-H&N-MAQ, Functional Assessment of Cancer Therapy-Head and Neck Scale-Malaysian Added Questions; EORTC QLQ-H&N35, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Head & Neck Module.

Table 2 HRQoL assessment instrument for other sub-population

HRQoL assessment instrument for other sub-population	n (%)	References
Cancer patient (adolescent and paediatrics)		
PedsQL™ Cancer Module	2 (66.6)	Rajagopal et al;[94] Tay et al[95]
Questionnaire adopted from Centre of Disease Control and Prevention (CDC) Youth Risk Behaviour Surveillance System	1 (33.3)	Alias et al[96]
Cancer patients' caregiver		
CQOLC	2 (50.0)	Gan et al;[97] Abdullah et al[98]
CarGOQoL	1 (25.0)	Ahmad et al[99]
ZBI	1 (25.0)	Ahmad et al[100]

Abbreviation: PedsQL, Paediatric Quality of Life Inventory™; CQOLC, Caregiver Quality of Life Index-Cancer; CarGOQoL, CareGiver Oncology Quality of Life; ZBI, Zarit Burden Interview

HRQoL Assessment Instruments for Other Sub-Population

For adolescent and paediatric cancer patients (n=3), the Pediatric Quality of Life Inventory™ Cancer Module (PedsQL Cancer Module) was employed in 2 studies (66.6%), while a questionnaire adopted from the CDC Youth Risk Behavior Surveillance System was utilized in 1 literature (33.3%). In the case of cancer patients' caregivers, the Caregiver Quality of Life Index–Cancer (CQOLC) instrument was used in 2 instances (50.0%) while the CareGiver Oncology Quality of Life questionnaire (CarGOQoL) and Zarit Caregiver Burden Interview Short Form (ZBI) instruments were each employed once, with utilization rates of 25.0% each, as demonstrated in Table 2.

DISCUSSION

Adult Cancer Patient Population

The systematic snapshot review's findings indicate a prevalent preference for generic HRQoL assessment instruments, notably the EORTC QLQ-C30, WHOQOL-BREF, EQ-5D-5L, and SF-36, among others. This predilection likely arises from their established psychometric properties, broad applicability across diverse patient populations, and comprehensive coverage of HRQoL dimensions. For instance, the EORTC QLQ-C30 offers a standardized framework for evaluating physical, emotional, and social aspects of HRQoL, making it a preferred choice in oncology research.[42, 67] Similarly, the WHOQOL-BREF and SF-36 enable a multidimensional assessment of quality of life across physical, psychological, social, and environmental domains, suitable for various health conditions (25, 93). The EQ-5D-5L, renowned for its reliability, validity and suitability for calculation of quality adjusted life years (QALY) for health economic evaluation of interventions, facilitates a detailed evaluation of health states with its five dimensions and response levels.[83]

However, it is essential to acknowledge the limitations of generic instruments in capturing disease-specific aspects of HRQoL, which may necessitate supplementary assessment tools tailored to specific patient populations and clinical conditions. Disease-specific HRQoL assessment instruments offer a higher degree of precision and relevance by catering to the unique experiences, signs, symptoms, concerns, and priorities associated with a particular disease.[36, 42, 54] For example, the FACT-B addresses the specific needs of breast cancer patients by assessing domains such as physical, social/family, and emotional well-being. By incorporating items related to body image, sexual functioning, and treatment side effects, the FACT-B ensures that the HRQoL assessment directly reflects the lived experiences of breast cancer patients, thereby enhancing patient engagement and assessment validity.[48, 51, 52] Furthermore, disease-specific tools are often designed to be sensitive to changes in disease progression, treatment response, and symptom management, providing additional benefits in monitoring treatment efficacy and informing clinical decision-making in randomized clinical trials. Examples include the visual disorder and muscle dysfunction domains incorporated in the EORTC

QLQ-BN20 for brain cancer and the voice and mouth functioning domains in FACT-H&N for head and neck cancer.[72, 86, 89] While some studies utilize internationally established disease-specific HRQoL assessment instruments, a minority develop their own assessment tools or adopt tools from other sources. However, the limited available resources may compromise the validity and reliability of such tools, rendering them unsuitable for establishing national or large-scale population-based studies.[60, 90] Therefore, it is crucial to prioritize the use of rigorously validated and internationally recognized disease-specific HRQoL assessment instruments to ensure the robustness and generalizability of study findings in the broader context of healthcare research and practice. If there is an absence of such assessment instrument, the self-developed tools should be properly validated by international standard before use.

As aforementioned, health economic evaluations rely significantly on HRQoL assessments to determine the impact of healthcare interventions on individuals' well-being. QALY serve as a pivotal metric in health economics, as they integrate both the quantity and quality of life experienced by individuals arising from interventions. QALY calculations involve multiplying the time spent in a specific health state by the utility or HRQoL score associated with that state. This integration allows policymakers and healthcare professionals to make informed decisions regarding resource allocation and treatment interventions, considering both the quantity and quality of life outcomes. Instruments like the EQ-5D-5L stand out in health economic evaluations due to their direct association with QALY, streamlining the assessment of healthcare interventions' impact on individuals' well-being. Unlike instruments such as the EORTC-QLQ-C30 and FACT-G, which often require mapping algorithms to convert scores into utility values for QALY estimations, the EQ-5D-5L simplifies the process by providing utility scores directly.[101-104]

Other Sub-Populations

It is also notable that the selection of HRQoL assessment instruments may vary based on the age group and specific needs of the patient population. For instance, the PedsQL Cancer Module is specifically designed to assess the HRQoL of paediatric cancer patients. This instrument recognizes the unique challenges faced by children and adolescents undergoing cancer treatment, including physical symptoms, emotional distress, and social functioning. By focusing on age-appropriate language, developmentally relevant domains, and child-friendly response formats, the PedsQL Cancer Module ensures that the assessment is sensitive to the needs and experiences of paediatric cancer patients.[94, 95, 105] Similarly, questionnaires adopted from the CDC Youth Risk Behavior Surveillance System cater to the specific needs and concerns of adolescents. These questionnaires address a wide range of health behaviors and risk factors relevant to adolescent populations, including substance use, sexual behavior, mental health, and physical activity.[96] By capturing data on these key domains, it allows healthcare providers and researchers to comprehensively evaluate the impact of cancer and its treatment on various aspects of a youngster's lives, leading to more effective patient-centered care, intervention planning and eventually policy development.

Among the included 88 literatures, only 4 studies have examined the QoL of cancer patients' caregivers. Prioritizing the inclusion of cancer caregivers in research studies is paramount due to their pivotal role in the care and support of individuals diagnosed with cancer. Caregivers shoulder a multitude of responsibilities, including assisting with daily activities, coordinating medical appointments, managing medications, and providing emotional support to cancer patients. The demands of caregiving can significantly impact caregivers' physical health, mental well-being, financial stability, and overall HRQoL. Research also indicates that the well-being of cancer caregivers directly influences patient outcomes, treatment adherence, and overall quality of care. Caregivers who experience high levels of distress or burden may struggle to provide optimal support to patients, leading to adverse outcomes for both caregivers and patients.[83, 97, 99, 100] By recognizing the interdependence of caregiver and patient well-being, government can adopt a holistic approach to cancer care that considers the needs of both patients and caregivers.

However, the present study has some limitations. First, the screening and selection process was performed independently by researcher 1 using the data extraction form predesigned by researcher 2 which might lead to risk of biasness. Second, searches were limited to English language only. It is possible that similar studies may have been published in other languages than English. Besides, this systematic review only includes the literatures published within the last 10 years, which may lead to publication bias and incomplete picture of literature. This approach may inadvertently favour newer research findings over foundational older, yet still relevant, studies.

The findings of this systematic review carry significant implications for healthcare systems, policymakers, and researchers, particularly from a societal perspective and within the framework of value-based healthcare. By delineating the utilization of HRQoL assessment tools across different cancer types in Malaysia, this review underscores the necessity of integrating

patient-reported outcomes into healthcare decision-making processes. From a research standpoint, collaboration between government and academia is encouraged to conduct more national population-based studies focusing on QoL assessment or even expand to a wider scope by incorporating more indirect cost element such as productivity loss. By having all these fundamental data, a national value assessment framework could be established to guide resource allocation and policy decisions within healthcare systems to maximise overall societal value.

CONCLUSION

This review identified various HRQoL assessment tools utilized across different cancer types and subpopulations in Malaysia, highlighting the diversity of instruments employed to measure patient-reported outcomes. These findings underscore the need for consistent and culturally relevant HRQoL tools to ensure accurate and meaningful assessments of cancer patients' and other sub-population's quality of life. Moving forward, collaboration between government entities and academic institutions is crucial to address existing gaps in HRQoL research, enhance the standardization of assessment tools, and promote equitable access to quality care, thereby supporting the broader adoption of value-based healthcare.

ACKNOWLEDGMENTS

The authors would like to acknowledge the support from the School of Pharmacy, Faculty of Health and Medical Sciences, Taylor's University, Malaysia, in providing resources for the present study.

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