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REVIEW ARTICLE

A systematic review of body image measures for people diagnosed with head and neck cancer (HNC)

Chindhu Shunmuga Sundaram[1,2] · Haryana M. Dhillon[1,2] · Phyllis N. Butow[1,2] · Puma Sundaresan[3,4] · Claudia Rutherford[5,6]

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Abstract

Purpose Head and neck cancer (HNC) is a relatively common cancer which causes a significant health burden, impacting individuals physically and psychologically. HNC treatment may result in facial disfigurement, eating and communication difficulties, and body image disturbances. We aimed to (1) identify HNC-specific patient-reported outcome measures (PROMs) used to assess body image, (2) evaluate their conceptual coverage, (3) appraise their development process and psychometric properties, and (4) determine appropriate body image PROM(s) for use in the HNC setting.

Methods Online databases were searched (July 2007–July 2017) for studies that assessed body image in patients with HNC. Studies were screened for eligibility. In addition, we searched three PROM databases for relevant PROMs. From available body image frameworks, we compiled a conceptual schema consisting of 18 clinically relevant body image issues important in the HNC setting, against which PROMs were assessed. Selected measures were appraised for psychometric characteristics, content, and readability.

Results A total of 245 records were retrieved. 18 studies with PROMs met our inclusion criteria, reporting eight PROMs. The PROM databases searched yielded 62 measures. After screening, eleven measures were short-listed and appraised. The Derriford Appearance Scale (DAS)-59, DAS-24, and body image scale (BIS) cover > 55% of issues within the body image conceptual schema; were developed based on literature, patient interviews, and clinician opinions; and have evidence of internal consistency (Cronbach alpha > 0.7), validity, and responsiveness.

Conclusions We recommend the DAS-24 and BIS as having adequate coverage of HNC-related issues, and suitable for use in future research.

Keywords Head and neck cancer · Body image · Patient-reported outcome measures · Validation · Content validity · Systematic review

Introduction

Head and neck cancer (HNC) includes cancers of the oral cavity, sinus and nasal cavity, pharynx (nasopharynx, oropharynx and hypopharynx), larynx, salivary glands, middle ear, and thyroid, generally arising in the epithelial lining or inner surfaces of these sites. According to World Health Organization (2014), every year, about five million people

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✉ Claudia Rutherford
claudia.rutherford@sydney.edu.au

[1] Centre for Medical Psychology and Evidence-based Decision-making, School of Psychology, Faculty of Science, University of Sydney, Sydney, NSW, Australia

[2] Psycho-Oncology Cooperative Research Group, University of Sydney, Sydney, NSW, Australia

[3] Radiation Oncology Network, Western Sydney Local Health District, Sydney, Australia

[4] Sydney Medical School, University of Sydney, Sydney, NSW, Australia

[5] Quality of Life Office, School of Psychology, Faculty of Science, University of Sydney, Sydney, NSW, Australia

[6] Sydney Nursing School, Cancer Nursing Research Unit (CNRU), University of Sydney, Sydney, Australia

are diagnosed with HNCs across the globe. High tobacco use in developing countries and increased human papilloma virus (HPV) transmission in developed countries have resulted in significantly more HNC cases globally [1–3]. Males are more likely to develop HNC than females [4, 5]. Despite clinical advances resulting in early diagnosis and effective treatment, locoregionally advanced HNCs have a high mortality rate estimated at about three million each year [6]. Most HNC patients face significant cancer and treatment-related morbidity given the proximity of their cancers to anatomical sites such as the oral cavity involved with functions (such as eating, swallowing, and communicating) and appearance.

HNC treatments may cause immediate effects such as disfigurement, scarring, or loss of a body part, as well as late side effects such as skin changes, reduced saliva, and swallow muscle fibrosis over many years [7]. HNC and its treatment may result in psychosocial, physical, or functional effects. Psychosocial outcomes include anxiety, depression, distress, and unmet needs [7]; physical sequalae include disfigurement, eating, or swallowing difficulty and pain; functional consequences include altered roles, difficulties performing everyday activities [8].

Individuals hold both a perception of themselves and perceptions of how they appear to others; these perceptions have potential to impact how they engage with the world [9]. As the head and neck region includes the face, critical to communication and engagement, potential disfigurement to the face or head and neck region may cause distress, embarrassment, lowered self-esteem, and threaten identity [9–11]. It can be anxiety-provoking, increase isolation, and limit one's sense of self during the period of adjustment to disfigurement and impairments [12], thereby impacting physical, psychosocial, and functional well-being [7]. Thus, one of the most important outcomes of HNC is body image disturbance [9, 12, 13], which has recently been defined in the cancer context, as self-perception of a change in appearance and displeasure and psychological distress associated with this change [14]. Body image disturbance has been shown to negatively affect health-related quality of life (HRQOL) [13].

The impact of the primary cancer (disease) and its treatment on body image disturbance may be moderated by a range of factors—personal characteristics, psychological factors, social factors, and environmental factors [13]. Body image is a combination of one's own perception and the reactions of others. People from different cultures perceive these impacts differently [9, 13, 15].

Conceptual frameworks of cancer-related body image have been developed to describe the components of body image in a cancer-specific setting. These are primarily cognitive-behavioral. Body image is conceptualized as incorporating cognitive (perceptions and thoughts), emotional (feelings), and behavioral experiences of the body [16–18]. However, most of the conceptual framework literature relates to breast cancer and fewer studies focus on body image constructs in the HNC population [17]. Similarly, a number of studies have focused on patient-reported outcome measures (PROMs) assessing body image in cancer patients specific to sites such as breast, or treatment types such as surgery [7, 13, 17, 19]. However, none have focused on measures suitable for assessing body image in HNC populations [13].

The paucity of body image measures specific to HNC populations may in part be the reason for limited evidence about the impact of HNC and its treatment on body image outcomes [20, 21]. Hence, such a measure, assessing the impact of body image disturbance as a result of the cancer and/or its treatment [19], is required to enable identification of those patients with needs, so appropriate supportive care interventions can be implemented.

To assist researchers and clinicians in selecting the most appropriate PROM of body image for use in HNC populations, we undertook a systematic review to identify body image PROMs used in HNC populations, assess their conceptual coverage against available body image frameworks, appraise their development and psychometric properties, and evaluate their readability levels. This review will also assist researchers developing new body image measures for HNC population.

Methods

This study was part of a larger systematic review to assess psychological distress, body image, and unmet needs in HNC patients registered with The International Prospective Register for Systematic Reviews (PROSPERO) ID CRD42018080677 [22, 23].

Literature search

We searched five electronic databases (Medline, Web of Science, PsycInfo, EMBASE, and CINAHL) from July 2007 to July 2017 for studies that assessed body image in HNC populations or reported a framework of body image in HNC. The search was limited to articles published from July 2007 corresponding to the introduction of intensity-modulated radiation therapy (IMRT) as HNC radiotherapy treatment of choice. IMRT uses advanced technology where radiation is targeted to the tumor's shape, in order to minimize side effects and restrict damage to healthy cells. The search included terms for "HNC" and "body image" (Electronic supplementary material). Additionally, we also searched the following: (1) three PROM databases (PROQOLID, Psycho-oncology database (POD), and Grid Enabled Measures Database (GEM)) for available body image measures; and, (2) web-based source (google scholar) for body image conceptual frameworks.

Study eligibility

Studies were included if the study sample was patients diagnosed with HNC (excluding thyroid cancer, which has minimal impact on quality of life or body image [24]), aged 18 years or over, and body image or appearance-related outcomes were assessed using a body image PROM. No minimum number of HNC patients is needed to be included for the study to be selected. Studies of mixed cancer groups were included if results were presented by cancer sub-groups separately. Conceptual frameworks were included if their focus was on body image disturbances in cancer. Since there were very few body image frameworks available on the whole, frameworks focusing on body image in cancer (and not HNC-specific) were included in the screening stage. We excluded discussion papers, editorial reviews, notes, case studies, letters to editor, conference proceedings, and studies published in languages other than English.

Screening

Retrieved studies were checked for duplicates, and titles and abstracts were screened against the eligibility criteria by one reviewer (CS). A second reviewer (HD) screened 10% of titles and abstracts selected at random. If all criteria were met, or relevance was ambiguous, full-text papers were obtained. Any disagreements between the reviewers were resolved through team discussion.

Data extraction

From included studies we extracted study's identifying information, aims, rationale, design and methods, study setting, participant characteristics, findings, effects, limitations, and PROMs used to assess body image and appearance outcomes. A second reviewer (HD) independently completed data extraction for a random 10% of included studies to check for consistency and found no disparities between reviewers. The original development and evaluation papers for the identified PROMs were sourced. We then assessed the PROMs' content coverage and psychometric properties.

Conceptual framework

Studies with conceptual frameworks describing body image in cancer were identified. Retrieved frameworks focused on body image specific to breast cancer patients [25–27], stress and coping with disfigurement and dysfunction [28], fear and avoidance following disfigurement [29, 30], and body image and cancer focusing on cognitive behavioral perspectives [18, 31]. None were specific to the HNC cancer. It was agreed by the research team that a conceptual framework with basic constructs of body image in HNC was unavailable. Hence, the research team decided to develop one.

From the included body image frameworks, PROMs, and with expert inputs, we identified 18 relevant body image issues important in the HNC setting to form a conceptual schema of body image issues specific to HNC (see Table 1). The expert team included a psycho-oncology expert with 25 years experience, a radiation oncologist with clinical and research interest in HNC, a behavioral scientist with experience in development of information resources for people with HNC, and a health psychology researcher with experience in development and evaluation of health-related conceptual frameworks and PROMs across multiple health conditions.

Content coverage

Items within the included PROMs were independently mapped to this conceptual schema by each member of the research team to assess content coverage and relevance (i.e., content validity) to HNC populations.

Judgments were based on the team's clinical experiences in the HNC setting. Discrepancies were resolved through group discussion until consensus was achieved. We determined the percentage of items in each PROM mapping onto the conceptual schema. For PROMs identified as having at least 50% of items relevant to the HNC setting, we assessed their psychometric properties.

Development and psychometric properties

PROM development and psychometric properties were evaluated against quality criteria adapted from the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist [32]. Data points included the following: item generation, item reduction, and psychometric analyses (reliability, validity, and responsiveness).

Reliability was examined in terms of internal consistency reliability (Cronbach alpha > 0.7) and test-retest reliability (stability or no change assessed at two time-points relatively close to each other) > 0.7.

Validity was examined in terms of factor analysis, content validity (qualitatively determined based on how comprehensive the development or item generation methods were), and any other empirical validation of measures such as cross-cultural validity, attempts to determine convergent, or divergent validity (validity between scales with scales from other measures).

Responsiveness was examined in terms of ability to detect change when change has occurred.

Note that the quality of studies evaluating the psychometric properties of available body image measures was not examined. The PROMs considered in this review were developed according to traditional Classical Test Theory (CTT, in

Table 1 Patient-reported outcome measures: domain analysis

Body image conceptual domains	DAS-59	DAS - 24	BIS	SIS	BICR	BICSI	BODY-Q	BIQ/FKB 20	BIQLI	ASI-R	MBSRQ
PROM related to HNC	✓	✓	✓	✓	✓						
Satisfaction with appearance	✓		✓			✓	✓	✓		✓	✓
Self-consciousness	✓	✓	✓		✓	✓		✓		✓	✓
Social consciousness	✓	✓		✓		✓	✓		✓	✓	✓
Self-esteem/self-concept	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓
Scarring			✓				✓				
Avoidant behaviour	✓	✓	✓	✓	✓	✓					✓
General psychosocial functioning	✓	✓	✓	✓		✓		✓	✓		✓
Psychosocial functioning (specific to body image)	✓	✓		✓	✓	✓		✓		✓	✓
Sexual functioning	✓	✓	✓				✓	✓	✓		
Physical functioning		✓		✓			✓				
Role functioning	✓	✓		✓				✓	✓		
Social functioning	✓	✓	✓			✓	✓		✓		
Noticeable change in appearance			✓	✓						✓	✓
Family and friends' response to appearance	✓	✓				✓					
Reliance on concealment of appearance		✓				✓			✓	✓	✓
Readiness to undergo additional procedures to improve appearance						✓		✓			
Ability to look at self	✓	✓	✓			✓	✓				
Others (not relevant to body image)		✓					✓	✓	✓	✓	✓
Number domains covered	12	14	10	8	3	11	8	8	7	7	9

DAS-59 Derriford Appearance Scale-59, *DAS-24* Derriford Appearance Scale-24, *BIS* body image scale, *SIS* Self Image Scale, *BICR* body image scale for cancer reconstruction, *BICSI* body image coping strategies inventory, *BIQ-20* body image questionnaire-20, *BIQLI* body image quality of life inventory, *ASI-R* Appearance Schemas inventory revised, *MBSRQ* multi-dimensional body-self relations questionnaire, ✓ present

contrast to newer methods of Item Response Theory and Rasch Measurement Theory [33–36]).

Readability index

The body image measures were assessed for readability [37]. Readability indices were calculated for each measure using an online readability calculator [38]: Gunning Fog Index and Flesch Reading Ease test. Gunning Fog Index indicates the years of formal education needed to understand the content. Flesch reading ease test scores indicate the ease with which a given text can be understood.

Results

The search retrieved 245 studies (after removing 97 duplicates), of which, 18 assessed body image or appearance outcomes in HNC populations (see Fig. 1). From these studies, eight body image PROMs were identified.

Searches of PROM databases identified 62 additional measures assessing body image or appearance-related outcomes, of which only three were cancer-specific or HNC-specific. Of the excluded 59, 21 did not assess body image; 29 were specific to other diseases such as inflammatory bowel disease, obesity, psoriasis, cystic fibrosis, or Parkinson disease; seven were specific to other cancer sites such as breast, liver, or urinary bladder; and two were duplicates identified previously. In total, 11 unique body image measures (eight from studies, three from PROMs databases) were identified and assessed for content coverage and relevance.

Consensus on content coverage was achieved among the research team after thorough review of all the measures (Table 1). Of the 11 measures, five were judged to have content applicable to HNC. Those determined not relevant to the HNC setting had items that were not understandable (Appearance Schemas inventory revised ASI-R) [39, 40]; validated and tested in non-clinical populations (body image coping strategies inventory (BICSI), body image quality of life inventory (BIQLI), and multi-dimensional body-self relations questionnaire (MBSRQ) and ASI-R) [41–45]; not validated in English (BIQ/FKB-20) [46, 47]; assessed body image specific to body contouring surgery patients (BODY-Q) [48, 49]; or were specifically developed for the breast cancer setting [13], meaning the content is not generalizable or relevant to other cancer types.

Of the five measures retained, three covered at least 50% of the 18 relevant content areas identified from the conceptual

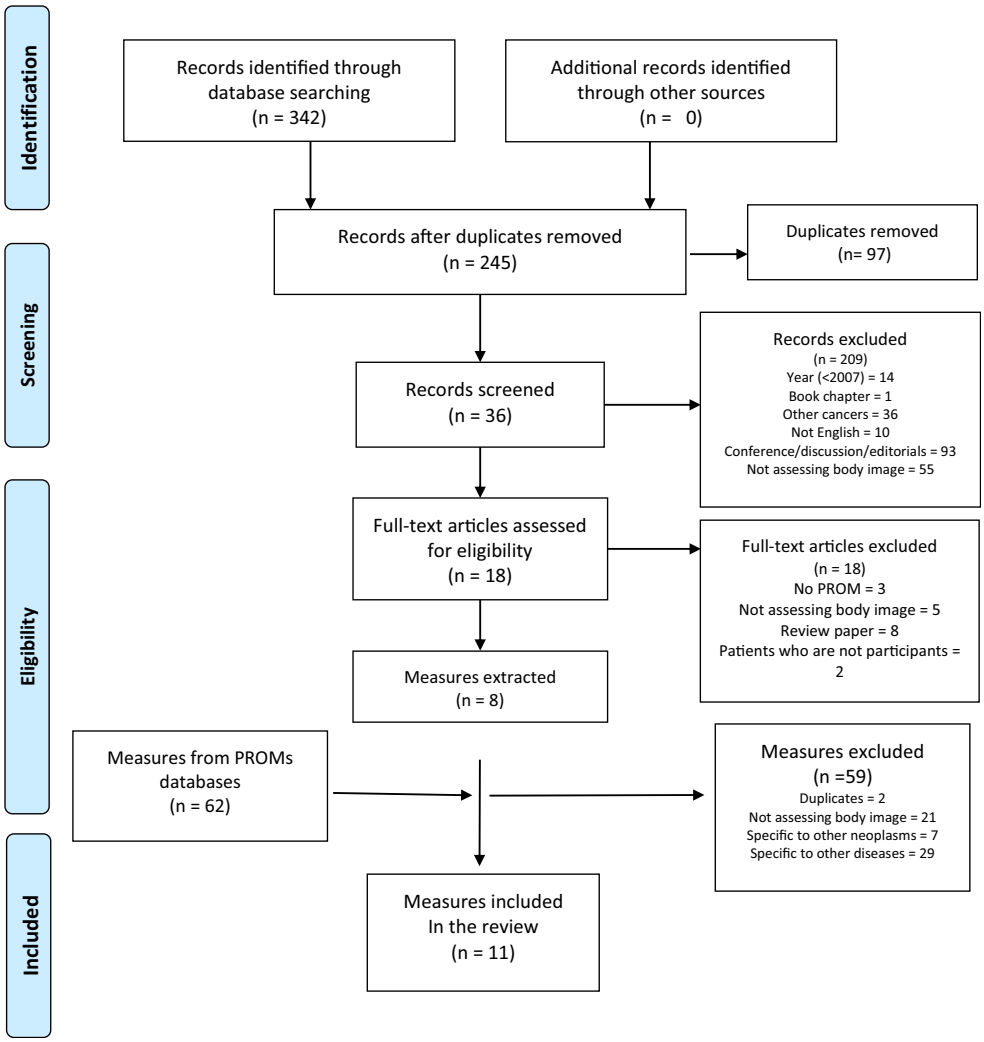

Fig. 1 Prisma flow diagram describing body image measures search

schema: the Derriford Appearance Scale-24 (DAS-24) covered 14 (78%), the Derriford Appearance Scale-59 (DAS-59) covered 12 (67%), and the body image scale (BIS) covered 10 (55%). Of the remaining two, the Self-Image Scale (SIS) covered 8 (44%), and the Body Image Screener for Cancer Reconstruction (BICR) covered 3 (16%) relevant content areas. The psychometric properties for the five measures are presented in Table 2 and summarized below.

Derriford appearance scale-59

The Derriford Appearance Scale-59 is a 59-item measure assessing appearance concerns across clinical and non-clinical populations. It includes five domains: general self-consciousness of appearance, social self-consciousness of appearance, sexual and bodily self-consciousness of appearance, negative self-concept, and facial self-consciousness of appearance [50, 51]. Items for the DAS-59 were generated through patient interviews, clinician interviews/expert opinions, and literature review [52]. The DAS-59 has been found to be reliable (Cronbach's alpha 0.98; test-retest reliability = 0.75), valid (item total correlations = 0.5), and sensitive to change in a clinical population (inclusive of postoperative plastic surgery patients) in appearance-related concerns [51]. The DAS-59 has been translated into Taiwanese, Nepalese, French, Dutch, Japanese, Korean, Spanish, Italian, and Swedish [53–58]. The Gunning Fog index and Flesch reading ease scores of DAS-59 were 16.20 and 33.08, respectively, indicating that less than 33% of people are likely to understand it, and the type of writing is equivalent to academic or scientific writing [37].

Derriford appearance scale-24

The 24-item DAS measure was developed from the DAS-59. It assesses appearance-related issues from a psychological perspective [50, 51, 59], including appearance-related distress and difficulties across a wide range of clinical and non-clinical populations. The original scoring of the DAS-24 produces a total score and no discrete scores based on multiple

Table 2 Patient reported outcome measures: psychometric analysis

Method[a]		DAS-59	DAS-24	BIS	SIS	BICR
Item generation	Literature	✓	✓	✓		✓
	Patient/person interviews	✓	✓	✓		
	Clinician interviews/Expert opinion	✓	✓	✓	✓	✓
Item reduction	Missing data for summary scores					
	Missing item data		✓			
	Factor Analysis	✓		✓		
Psychometric analyses	Internal consistency reliability	✓	✓	✓	✓	
	Test-retest reliability	✓	✓	✓		
	Content validity	✓	✓	✓	✓	
	Item total correlations	✓	✓	✓		
	Convergent/discriminant (or divergent) validity	✓	✓			
	Hypothesis testing		✓	✓		
	Translated into other languages	✓	✓	✓		
	Responsiveness	✓	✓	✓		

DAS 59 Derriford Appearance Scale-59, *DAS 24* Derriford Appearance Scale-24, *BIS* body image scale, *SIS* Self Image Scale, *BICR* body image scale for cancer reconstruction, ✓ present

[a] Criteria based on the COSMIN checklist

scales or factors [59]. However, recent validation studies identified two sub-scales—general self-consciousness, and sexual and body self-consciousness—and showed that the one-factor model fit well only when "not applicable" responses were treated as missing data [60, 61]. Items in the DAS-24 were found to be strongly correlated with the original DAS-59 (0.88). Psychometric analysis demonstrated adequate reliability (Cronbach's alpha 0.92; test-retest reliability = 0.82), validity (convergent validity; item total correlations = 0.46–0.72) and responsiveness in reconstructive plastic surgery patients with appearance concerns [59]. The DAS-24, like the longer version, has been translated into multiple languages including Armenian, Dutch, French, Portuguese, Swedish, Italian, Korean, and Japanese [8]. The Gunning Fog index and Flesch reading ease scores of DAS-24 were 12.38 and 41.17, respectively, indicating that 90% of people would require a senior high school level of education to be able to read it [37].

Body image scale

The body image scale is a 10-item measure developed in association with the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Study Group following their guidelines for PROM development [62, 63]. It was developed for use in a wide range of oncology populations with no disease site-specific items [7]. The items in the BIS focus on affect, behavior, and cognition. Psychometric analysis found good internal consistency reliability (Cronbach's alpha 0.78), test-retest reliability ($r > 0.70$), validity (content and discriminant validity; item total correlation 0.30), and responsiveness in a sample of cancer patients [7, 62]. The BIS has been translated into the following languages—Arabic, French, Korean, and Spanish—and validated in Dutch, Portuguese, and Greek [64–71]. The Gunning Fog index and Flesch reading ease scores of BIS were 6.03 and 62.86, respectively. The scores indicate that the text is likely to be understood by 83% of people and those with a reading grade of 8–9 [37].

Self-image scale

The Self-Image Scale is an 18-item measure assessing self-image of HNC patients. There are three domains: body image, self-esteem, and integrity. Items were generated based on expert opinion only. Face validity was derived from five experts who assessed the measure for relevance and appropriateness. Reliability ($r = 0.7$) was assessed in 20 patients with HNC [72]. The content validity was measured by the item-level content validity index (I-CVI) and scale-level content validity index (S-CVI) based on Polit and Beck [73–76], and only items with I-CVI above 80% (0.8) were included in this measure. The Gunning Fog index and Flesch reading ease scores of SIS were 6.15 and 70.12, respectively. The scores demonstrate fairly easy verbal description which is likely to be understood by 88% of people and those with a reading grade level of 7 [37].

Body image screener for Cancer reconstruction

The BICR is a brief 4-item measure assessing body image in cancer patients undergoing reconstructive surgery. The items

were constructed based on information derived from the body image literature and expert opinion of a multidisciplinary team, but no evaluation of reliability or validity has been reported [77]. The Gunning Fog index and Flesch reading ease scores of BICR were 10.04 and 44.64, respectively, indicating difficult verbal description and a reading grade level of 13–16 years [37].

Discussion

Our review identified a number of measures assessing body image in general; however, only five included were found addressing body image issues relevant to patients with HNC, among which two (SIS and BICR) [72, 77] had a limited development process. Their item generation did not involve an extensive literature search or input from patients through focus groups/interviews or both. Although clinician interviews and expert opinions are important, input from patients is valuable to identify issues important and specific to the patient population of interest. Patient interviews can uncover important issues that may not be known to health professionals and clinicians.

In addition, the BICR and SIS have no published evidence of validity, reliability, or responsiveness [72, 77]. Conversely, DAS-59, DAS-24, and BIS have undergone extensive psychometric testing, providing support for their validity, reliability, and responsiveness [50, 51, 59, 62]. The minimal important difference (MID) has emerged as a concept important in defining the relevance of measured changes to clinical outcomes. Unfortunately, none of the measures included in our review have MID available. This is an important area for development in future research. While psychometric tests indicate good performance, their results are limited to the sample(s) and context(s) in which they were evaluated. Hence, consideration of content validity is essential when selecting measures for use in clinical research. Content mapping against a conceptual framework indicates how relevant and comprehensive the content in a measure is to the concepts important in each clinical setting or application.

Available body image conceptual frameworks focus on breast cancer or fail to comprehensively represent the experience of HNC patients [13]. Lack of an established conceptual framework of body image disturbance specific to HNC patients [13, 62] led to the research team developing a novel conceptual schema for this review [78]. Body image includes a range of issues, and different PROMs address different aspects of body image. It is crucial to have well-defined parameters to guide selection of a clinically robust body image measure for use in HNC populations and clinical settings. Body image disturbance in HNC is different from other cancers (such as breast) because of its visibility, impact on speech, swallowing, and personal identity [13]. Hence, researchers need to consider which aspects a specific measure covers to ensure that the most appropriate one is selected to assess relevant patient-reported outcomes (PROs). Both the HNC-specific body image conceptual schema developed in this study and the evaluation of the content of existing body image PROM's can be used by researchers and health professionals in the future to select appropriate PROMS in the HNC setting.

Our conceptual mapping revealed that some available measures assess a number of relevant body image concepts including self-consciousness, self-esteem, self-concept, avoidant behavior, and impact on different aspects of functioning in-depth. The DAS-59, DAS-24, and BIS measures most comprehensively assess relevant body image domains. Scarring and its impact, however, are not assessed by the BICR or SIS measures. Scarring and disfigurement may be unavoidable outcomes of HNC treatment; therefore, a PROM for use in HNC patients should capture these aspects of body image disturbance [13]. Both scarring and disfigurement can impact self-esteem and contribute to impaired psychosocial functioning, depression, and anxiety. The face is our representation to the outer world, meaning that any disturbance to facial appearance may bring about distress and fear of social situations [9].

There is overlap in concepts covered by the available measures (e.g., self-esteem, self-concept, social-consciousness, noticeable change in appearance, self-consciousness, and ability to look at self). DAS-59 and 24 and BIS have the most comprehensive conceptual coverage, addressing many aspects of body image relevant to HNC. Whereas, measures such as BICR and SIS are more specific in their content thereby addressing only particular aspects of body image. Since DAS-59 has been shortened and standardized, DAS-24 and BIS are recommended for use to assess body image and appearance outcomes in HNC populations.

An important point to note is that the term "HNC" includes a diverse group of related cancers that arise in the head and neck region: mouth, throat, nose, sinuses, and voice box. Cancers and treatments to these varying anatomical sites may cause different difficulties, disfigurements, and disturbances. Thus, the tumor site, stage of disease (and therefore extent of treatment), purpose of the study, the construct(s) of the measure, and feasibility concerns should be considered when choosing outcome measures for use in a particular clinical or research scenario.

The length and complexity of measures are likely to impact feasibility of data collection in HNC populations, due to the cognitive load associated with decoding these measures in the context of emotional and physical demands of the disease and treatment. HNC patients are a diverse group in terms of tumor stage, tumor type, education, health literacy, culture, and languages [79]. Considering this, using measures with high readability scores will make it difficult for patients to complete assessments themselves, and they may require assistance from a member of staff.

Across countries, the incidence rates of HNC are on the rise as a result of tobacco usage and HPV [2, 3]. The demographics of HNCs are also changing as a result of this increase in HPV-related cancers. HPV-related HNC tends to affect younger, otherwise well individuals and contribute to a better prognosis and survival outcomes. It is therefore important to improve survivorship care by including assessment of body image outcomes.

Body image outcomes have a positive influence on a range of domains such as physical, form, functional, psychological, and social, thereby contributing to HRQOL. Since HNC treatment affects HRQOL adversely, the primary objective is therefore to reduce body image disturbance, and, as a result, improve HRQOL [80].

However, few psychometrically and clinically robust PROMs are available to assess body image outcomes in HNC patients. Available measures were developed in English; some have been cross culturally validated in a limited number of languages. With increasing immigration internationally, there is a need for cross-cultural adaptation of measures into other languages.

Strengths, limitations, and implications

This review was systematic, comprehensive, and assessed PROM quality based on COSMIN checklist [32]. The search strategy was exhaustive, and this is the first study to develop a conceptual schema of body image disturbance in HNC, review available for body image measures used in patients with HNC, and comprehensively evaluate their content, development, and psychometric properties in order to determine their suitability for use in HNC clinical research.

Potential limitations include limiting articles to English language, excluding conference abstracts where there could be information about ongoing relevant research not yet published. Although BIQ/FKB-20 was excluded in this review because of language, it may be relevant to studies performed in Germany. This review did not assess whether the PROMs are suitable to be used in clinical practice with different criteria and considerations. However, it provides researchers and health professionals a rigorous comparison of the available measures.

Conclusions

This review recommends two body image PROMs—DAS-24 and BIS—as having adequate body image issues relevant to patients with HNC and evidence of psychometric properties. These PROMs can be used in future research with body image endpoints. This review also highlights the paucity of body image literature specific to HNC populations. All available body image measures relevant to HNC were identified, and their conceptual coverage and psychometric properties assessed. Selection of PROMs should be informed by the research aims, population of interest, and study treatment. PROMs with evidence of a rigorous development and evaluation process should be used. Future research is needed to validate the available measures in HNC and undertake language translations and cross-cultural validation.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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