



REVIEW ARTICLE (META-ANALYSIS)

Identifying Gaps in Research on Rehabilitation for Patients With Head and Neck Cancer: a Scoping Review

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Abstract

Objectives: Examine the amount and nature of research activity in head and neck cancer (HNC) rehabilitation; highlight publication trends, including information about the authors, settings, and study designs; and identify gaps in the existing literature.

Data Sources: Eligible studies were identified using PubMed, Embase, and CINAHL databases.

Study Selection: Inclusion criteria included human subjects, English language, publication between 1/1/1990 and 4/30/2017, HNC patients at any timepoint in disease, and evaluation of rehabilitation outcomes as described by the International Classification of Functioning, Disability and Health (ICF) framework. Exclusion criteria included intervention or outcome not specific to rehabilitation or the HNC population, and protocols or abstracts without corresponding full manuscripts.

Data Extraction: An established 6-step scoping review framework was utilized to develop the review protocol. A 3-level review was then performed. Data on eligible studies were collected using a Research Electronic Data Capture (REDCap) tool.

Data Synthesis: Among 2201 publications, 258 met inclusion criteria. Publication rate increased by 390% over the study timeframe. Most studies were observational (n=150). Few were interventional (n=35). The most common interventions focused on chewing or swallowing (n=14), followed by exercise (n=10). Most primary outcome measures fit the ICF definition of impairment; fewer fit the definitions of activity limitation or participation restriction.

Conclusions: Although research volume in HNC rehabilitation is increasing, the literature is dominated by small (≤ 100 patients), outpatient-based observational studies involving chewing or swallowing-related impairments. More prospective studies in multidisciplinary domains across the cancer care continuum are needed. There is particular need for interventional studies and prospective observational studies. Future studies should evaluate clinically-relevant activity limitations and participation restrictions. Rehabilitation professionals have an important role in the design of future HNC rehabilitation research.

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As of 2015, there were nearly half a million individuals with head and neck cancer (HNC) in the United States.¹ Relative survival rates increased from 54.7% to 65.9% between the 1990s and

2000s due to advances in chemoradiation treatment and radiotherapy techniques.² As with other cancers, improved survival has increased the attention of national cancer organizations on chronic and survivorship care, including rehabilitation needs.^{3,4}

The head and neck region contains structures that are critical for speech, swallowing, neck and upper extremity function, and cosmesis. The necessarily invasive treatment of HNC, including tumor resection, cervical lymph node dissection, and concurrent

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chemoradiation,⁵ makes HNC patients particularly vulnerable to functional loss.^{3,6-14} Resulting nutritional changes, impairments, activity limitations, and participation restrictions often require coordination of complex interventions that combine evaluation and treatment by rehabilitation professionals.¹⁵⁻¹⁸

Although there are many clinical approaches to the rehabilitation of the HNC patient, research aimed at evaluating the effectiveness of interventions is limited. A recent bibliometric analysis of the landscape of cancer rehabilitation research concluded that while cancer rehabilitation research has accelerated markedly over the past 25 years, even surpassing the rate of increase of general rehabilitation research, diagnoses of breast, prostate, and lung cancer encompass the majority of this volume.¹⁹ In contrast, a review of research on rehabilitation for HNC survivors identified only 39 interventional studies published during a similar timeframe, 2003-2016.^{19,20}

In order to meaningfully expand HNC cancer rehabilitation research, it is imperative to understand the scope of what has previously been published in this area. Although Rodriguez et al²⁰ began this important work by identifying interventional studies in HNC rehabilitation, a broader review of the HNC rehabilitation literature is needed. The purpose of our study was to examine the amount and nature of rehabilitation research activity in HNC rehabilitation; highlight publication trends in this area, including information about the authors, setting, and study designs; as well as identify gaps in the existing literature to direct future research.

To achieve these aims, we performed a scoping review of HNC rehabilitation research that included all study types and time points across the cancer care continuum. Scoping reviews assess a broad spectrum of research in a field and are effective for review of research topics with varied study designs.²¹ Our review also sought to characterize the specific outcomes most commonly used in HNC clinical rehabilitation research using the International Classification for Functioning, Disability and Health (ICF) framework.

Methods

Design

We used the 6-staged scoping review methodological framework originally proposed by Arksey and O'Malley²¹ and advanced by Levac et al.²²

Setting and participants

The protocol was prepared, reviewed, and revised by an advisory board consisting of members of the American Academy of Physical Medicine and Rehabilitation's Cancer Rehabilitation Physician Consortium. The original search strategy was developed by 5 members of the research team (S.P., S.O., A.N.H., S.S., L.G.) in conjunction with a rehabilitation research librarian.

List of abbreviations:

HNC	head and neck cancer
ICF	International Classification of Functioning, Disability and Health
QOL	quality of life
REDCap	Research Electronic Data Capture

Search strategy

Searches were conducted in the PubMed, Embase, and CINAHL databases using the search terms *head and neck neoplasm* and *rehabilitation* (complete search strategy available in [supplemental appendix S1](#), available online only at <http://www.archives-pmr.org/>). Inclusion criteria included: (1) human studies; (2) English language; (3) published between January 1, 1990, and April 30, 2017; (4) population of HNC patients at any stage from diagnosis through survivorship; (5) rehabilitation interventions or outcomes, including impairments, activity limitations, and participation restrictions, as defined by the ICF framework,³ or interventions or outcomes relevant to the rehabilitation team (ie, physiatrists, physical therapists, occupational therapists, speech language pathologists, rehabilitation psychologists, recreation therapists, exercise physiologists, or vocational counselors). Not only research articles but also reviews, opinions, book chapters, and guidelines were included if they met the above criteria. Studies were excluded if: (1) both the intervention and outcome were not related to rehabilitation (eg, exclusively psychological and psychiatric, surgical, or dental); (2) the study included a mixed population (eg, multiple cancer types or head and neck surgical patients without cancer) and lacked specific interventions or outcomes specific to the HNC population; (3) the study had quality of life (QOL) outcomes without specific functional outcomes. During review of the full text, publications were also excluded if they consisted only of a protocol, abstract, or poster without a corresponding full manuscript.

Three levels of review were performed. The first and second levels of review were performed by 5 members of the research team (S.P., S.O., A.N.H., S.S., L.G.) and involved examination of the title, keywords, and abstract by 2 separate reviewers to determine if the article fit the inclusion criteria. The titles appropriate for the scoping review were then distributed evenly among all 7 members of the research team, and a third level of review was performed. The third level of review included examination of the full text by a third reviewer to verify inclusion. If the article was included, this reviewer also performed the data collection.

Data collection

Study data were collected and managed using Research Electronic Data Capture (REDCap),^a a secure, web-based application hosted at the University of Washington.²³ REDCap is "designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources."^{23(para.2)} All authors participated in design of the REDCap data collection instrument ([supplemental appendix S2](#), available online only at <http://www.archives-pmr.org/>), and the instrument was piloted by all members of the research team in order to ensure consistent interpretation of data collection questions. Notably, identification of journal or text type (eg, surgical vs rehabilitation) was not included in the REDCap data collection survey. Given the iterative nature of the scoping review process,^{21,22} all members of the research team agreed that it was acceptable to collect information on journal or text type retrospectively. In order to collect the information on journal or text type, 1 reviewer (S.P.) examined the mission statements on each journal's website or book summary page to determine their primary publication focus.

Terms and measures

The total numbers of articles included and excluded from each round of review were recorded. The specific items collected in the REDCap instrument included: (1) Bibliographic information, such as title, first author, publication year, and journal. Journal or text type was collected retrospectively, as above; (2) First-author demographics, including primary credential (eg, speech language pathology), professional affiliation (eg, academic), and study location (eg, United States). This information was typically available in the article's full text. In the rare instance when the author's primary credential, affiliation, or location was not available in the text, an online search was conducted; (3) Study design features, including population size (<25, 25-100, or >100) and study design type (interventional, observational, or other). Study design type was classified using standard definitions of interventional study and observational study from the United States National Library of Medicine's ClinicalTrials.gov Glossary of Common Site Terms²⁴; (4) For articles that met the definition of an interventional study, we identified characteristics of the intervention itself, including type (eg, exercise program), setting (eg, inpatient), and timing relative to the patient's treatment course (eg, active treatment); (5) For articles that met the definition of either an observational or interventional study, we characterized the primary outcomes based on the ICF category (eg, impairment, activity limitation, participation restriction); notably multiple ICF categories could be selected by the reviewer. Per the ICF model, impairments are defined as "problems in body structure or function."²⁵ Activity limitations are defined as "difficulties that an individual may have in

executing tasks."²⁵ Participation restrictions are defined as "problems that an individual may experience in life situations."²⁵ During the data analysis phase, the primary outcome was coded as mixed if multiple outcome measures were used, none was designated as primary, or they represented different ICF categories. The primary outcome was coded as other or none if it did not fit the ICF model (eg, cost-effectiveness). Secondary outcomes were also categorized (impairment, activity limitation, or participation restriction).

Data analysis

Data from the REDCap tool was downloaded into a Microsoft Excel version 16.12^b for Macintosh spreadsheet and analysis was carried out using descriptive statistics. For example, the number of studies of a given category (eg, interventional) was counted and the percentage of that category relative to total included publications was calculated.

Results

We retrieved 2228 results from all sources; after removal of 27 duplicates, the total was 2201 articles. After 3 rounds of independent review, 258 articles met the inclusion criteria for analysis (fig 1).

Author demographics

There were 206 unique first authors. Of these, most were physicians (n=79; 38%) or speech language pathologists (n=36;

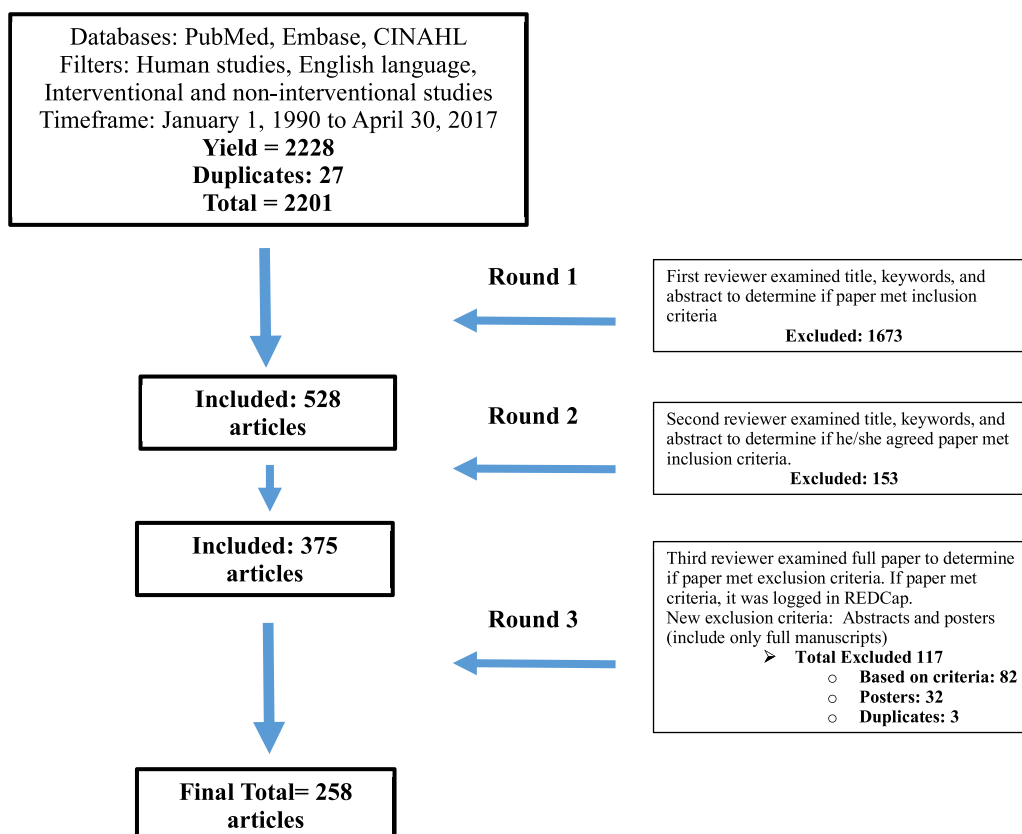


Fig 1 PRISMA diagram.

17%). Most authors had a primary academic affiliation (n=190; 92%), and nearly two-thirds were located outside of the United States (n=133; 65%) (table 1).

Bibliographic information and publication trends

The publication rate increased over time, roughly doubling every 10 years, with more than half of the articles published after 2010 (n=145; 56%) (fig 2 and 3). The average number of articles published during the first 3 complete years of the search (1990-1992) was 5.3 per year, while the average number published during the last 3 complete years of the search (2014-2016) was 20.7, or a 390% increase over time. Articles were published in 105 different journals, most of which were classified as specialty surgery or oncology journals or texts; only 8 articles (3%) were published in rehabilitation medicine journals or texts (table 2).

Study design

Nearly three-quarters of included articles were clinical studies (n=185; 72%). Of these, the majority were observational (n=150); 35 studies were interventional (tables 3 and 4). The sample size was fewer than 100 in most clinical studies (see tables 3 and 4). Opinion pieces, book chapters, reviews, and guidelines made up the remainder of the articles (n=73; 28%). Of these, 14 were systematic reviews. Eight (57%) of the systematic reviews were focused on speech and swallow topics in HNC, 3 (21%) were focused on identifying QOL and functional outcome measures in HNC populations, 2 (14%) reviewed topics in shoulder and neck health of the HNC cancer patient, and 1 (7%)

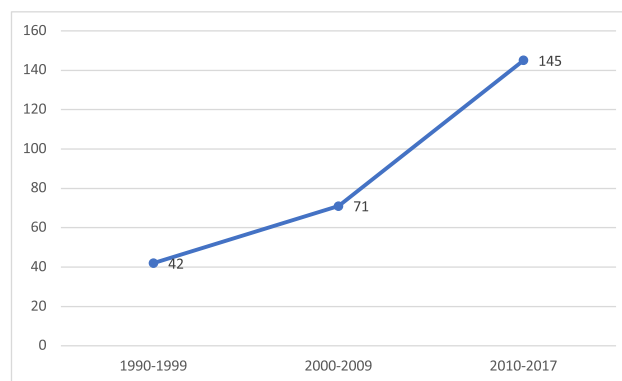


Fig 2 Number of publications over time by decade.

reviewed exercise in an HNC populations. The complete list of articles is included in supplemental appendix S3 (available online only at <http://www.archives-pmr.org/>).

Intervention

Among the 35 interventional studies, the most common interventions focused on chewing and swallowing (n=14; 40%). The next most common intervention type was administration of aerobic or resistive exercise (n=10; 29%). Five studies examined the effect of a voice or speech intervention (14%). Three studies examined the effect of a multidisciplinary rehabilitation intervention (9%), 2 examined an alternative and complementary medicine intervention (6%) and only 1 specifically examined an intervention performed by a physiatrist. There were no studies that examined interventions specific to vocational counseling, rehabilitation psychology, or recreation therapy. Nearly all interventional studies were performed in an outpatient setting (n=33; 94%) (see table 3). Most enrolled participants during active cancer treatment (n=11; 31%) or in the survivorship phase (n=15; 43%). No interventional studies specifically evaluated a pretreatment population.

Outcomes

Among the interventional studies, the majority of the primary outcome measures fit the ICF definition of impairment (n=25; 71%); fewer fit the definition of activity limitation (n=7; 20%) or participation restriction (n=3; 9%). The observational studies often measured primary outcomes that fit our definition of the mixed ICF category (n=62; 41%). Of the observational studies with a primary outcome that fit a single ICF category (n=79; 53%), most measured impairment (n=48; 61%); followed by activity limitations (n=22; 28%); relatively few measured participation restrictions (n=9; 11%). The ICF model could not be applied to the remainder of the primary outcomes (n=9; 6%).

Discussion

Our scoping review of HNC rehabilitation research highlights several important findings related to the amount of research activity in HNC rehabilitation, publication trends in this area, as well as gaps in the existing literature.

Table 1 Characteristics of the first authors of the included HNC rehabilitation research publications

Characteristic	No. of First Authors (%), n=206
Primary Credential	
Physician*	79 (38)
SLP	36 (17)
PhD	25 (12)
Nurse†	13 (6)
PT	10 (5)
DDS‡	9 (4)
OT	1 (0.4)
Other	14 (7)
Unlisted	19 (9)
Affiliation	
Academic	190 (92)
Private	6 (3)
Industry	0
Other/Unknown	10 (5)
Location	
United States	73 (35)
Other	133 (65)

Abbreviations: SLP, speech language pathologist; PT, physical therapist; OT, occupational therapist.

* MD; DO; MBBS; ± PhD.

† RN, NP; ± PhD.

‡ This category was used for all dental providers including DMD, OMFS; ± PhD.

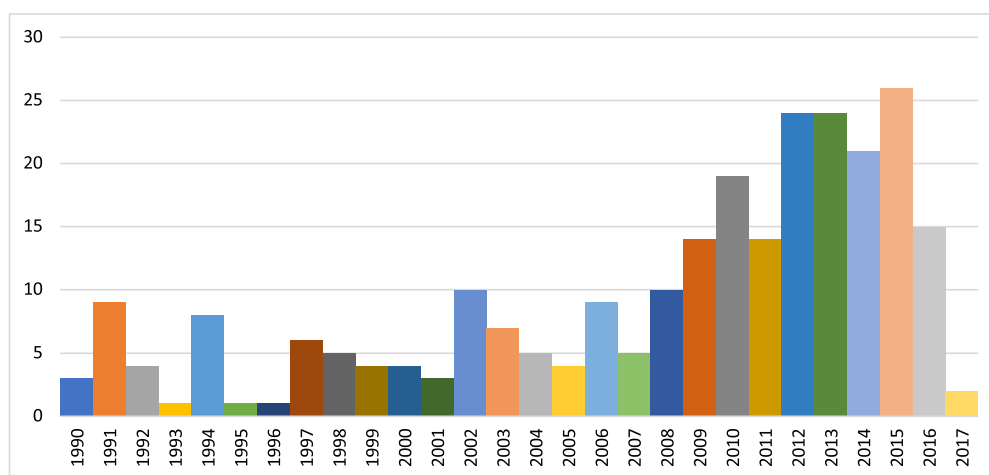


Fig 3 Number of publications over time by year, 1/1/1990 through 4/30/2017.

Commensurate with prior bibliometric analyses of both general rehabilitation and cancer rehabilitation research, the amount of research activity in HNC rehabilitation has increased over time. However, the 390% increase in HNC rehabilitation publications is dwarfed by the 810% increase in cancer rehabilitation publications and the 1056% increase in general cancer research publications over the same timeframe.¹⁹ Although the rehabilitation needs in the HNC population are increasingly recognized, HNC patients remain an underrepresented population in cancer rehabilitation research.

Our review also identified several important trends in the HNC rehabilitation literature, which provide a framework for understanding the gaps in the literature. First, the HNC rehabilitation literature base is dominated by small (≤ 100 patients), outpatient-based, retrospective observational studies. There is significant need for both interventional and prospective observational studies. Although prospective observational studies have limitations, the importance of these studies should not be overlooked. Many of the observational studies captured by our review tested the feasibility of a rehabilitation intervention or obtaining a rehabilitation outcome; as such, they may provide preliminary data for future controlled trials.

Table 2 Number of articles on HNC rehabilitation research published in different types of journals or texts

Type	No. of Journals/ Texts (%), n = 105	No. of Articles (%), n = 258
Surgical	31 (29)	120 (47)
Oncological	33 (31)	73 (28)
Swallowing and speech rehabilitation	9 (9)	21 (8)
Rehabilitation medicine	5 (5)	8 (3)
Physical therapy	3 (3)	7 (3)
Palliative/pain	5 (5)	6 (2)
Dental	2 (2)	3 (1)
Cochrane database	1 (1)	3 (1)
Sports medicine	2 (2)	2 (1)
Mixed/other	14 (13)	16 (6)

Another important trend is the focus on impairment-driven outcomes. The majority of primary outcomes in both the observational (61%) and interventional (71%) studies measured impairment, while significantly fewer observational (28%) and interventional (20%) studies addressed activity limitations. Notably, only 9 observational (6%) and 3 interventional studies (9%) had primary outcomes addressing participation restrictions. Although impairments are often chosen as outcome measures because they are objective and well defined, the degree of impairment does not necessarily correlate with function and QOL.^{27,28} In order to implement effective rehabilitation interventions to improve function and QOL, it is important to

Table 3 Design characteristics of the HNC rehabilitation interventional studies

Characteristic	No. of Interventional Studies (%), n = 35
Methodology	
RCT	31 (89)
NRCT	4 (11)
Population Size	
<25	4 (11)
25-100	30 (86)
>100	1 (3)
Intervention	
Timing	
Pretreatment (prehab)	0 (0)
Active treatment	11 (31)
Post-treatment (survivorship)	15 (43)
Mixed/unknown	9 (26)
Setting	
Inpatient	1 (3)
Outpatient	33 (94)
Mixed/unknown	1 (3)
Primary Outcomes	
Impairment	25 (71)
Activity limitation	7 (20)
Participation restriction	3 (9)

Abbreviations: NRCT, nonrandomized controlled trial; RCT, randomized controlled trial.

Table 4 Design characteristics of the HNC rehabilitation observational studies

Characteristic	No. of Observational Studies (%), n = 150
Population Size	
<25	38 (25)
25-100	75 (50)
>100	37 (25)
Methodology	
Retrospective reviews*	86 (57)
Prospective cohort	44 (29)
Case report/series	13 (9)
Survey validation	7 (5)
Primary Outcomes	
Single ICF category	79 (53)
Impairment	48 (61)
Activity limitation	22 (28)
Participation restriction	9 (11)
Mixed ICF categories	62 (41)
Other	9 (6)

* Includes retrospective cohort, case-control, cross-sectional, case-crossover, ecological, and proportional mortality designs (These²⁶).

understand the potential effect of an intervention on activity limitations and participation restrictions; as such, future HNC literature should include outcomes that move beyond impairment-driven outcomes.

The complex interplay of the multiple levels of the ICF makes involvement of rehabilitation experts essential to delivering quality cancer care.¹⁵ Our review suggests, however, that there is opportunity to engage more rehabilitation team members in HNC rehabilitation research. In particular, there were relatively few first authors who were primarily credentialed as physical or occupational therapists. The designation of the first author is important because it influences study design and objectives. For instance, more than half (19) of the 35 interventional studies examined interventions that are within the scope of speech language pathology (40% swallowing; 14% speech). Additionally, more than half (8) of the 14 systematic reviews identified by our search focused on speech and swallow topics. This is consistent with our finding that speech language pathologists made up the second largest group of first authors, preceded only by physicians.

While physician roles are more heterogeneous depending on subspecialization, it is notable that 3-quarters of publications on HNC rehabilitation were published in oncology and surgical journals and texts. The increasing number of articles published in these venues may suggest a growing interest in rehabilitative care within the medical and surgical oncology communities. Only 8 articles (3%) were published in rehabilitation medicine journals. This disparity, when paired with the finding that only 1 study examined a physiatrist-led intervention, suggests that HNC rehabilitation is an area in which to increase physiatry's contribution to the literature.

The need for increased participation by physiatrists is also supported by the relative scarcity of multidisciplinary interventions in the interventional studies captured by both our review (n = 3; 9%) and the recent review by Rodriguez et al²⁰ (n = 3; 8%). As leaders of the multidisciplinary rehabilitation team, physiatrists have an important perspective on the complex supportive care needs of cancer patients. It is likely that involvement of physiatrists, as well as other under-represented members of the

rehabilitation team, including physical therapists and occupational therapists, rehabilitation psychologists, recreation therapists, and vocational counselors, would promote the design and implementation of studies that move beyond impairment-driven outcomes and address patients' activity limitations and participation restrictions to optimize function.

It is notable that only one-third of the publications identified in this review were authored by investigators in the United States. While this discrepancy could be due to increased interest in rehabilitation research in locations in which healthcare systems are more universal and have different research priorities such as cost containment, another possibility is that the difference is related to disease prevalence. There are more than 10 times as many cases of HNC worldwide compared with the United States alone (680,000 vs 63,000, respectively),²⁹ yet there were fewer than twice as many publications on HNC rehabilitation outside of the United States.³⁰ The highest incidences of oral cavity and lip cancers are in Melanesia, South-Central Asia, and Central and Eastern Europe, with larynx cancers highest in the Caribbean and Central Europe and nasopharynx cancers in Southeastern Asia.^{29,30} While our review did not classify studies by country, future work may consider correlating incidence and prevalence data to study population location. There is also room for further investigation into the cost-benefit of rehabilitation strategies for HNC patients in different healthcare environments.

Our review revealed some important differences compared to the recent review by Rodriguez et al.²⁰ Although our review captured a similar number of interventional studies (35 vs 39), only 23 of those studies were common to both reviews. Of these 23 studies, only 13 were coded as interventional by our criteria; the remainder were coded as observational. This difference can be explained by our use of the ClinicalTrials.gov definition of interventional study, which restricts the interventional category to controlled trials.²⁴ Despite our relatively strict criteria for interventional studies, our review captured 22 interventional studies that were not captured by the Rodriguez review.²⁰ This difference can be explained by our broad inclusion criteria, which allowed a larger number of articles to be included and classified overall. This difference cannot be explained by our longer inclusion timeframe, as only 2 of these 22 interventional studies were published before 2003 (the first year of the Rodriguez review²⁰), or by the fact that we included HNC populations across the cancer care continuum rather than only survivors, as our review did not reveal any interventional studies in a pretreatment population.

We also identified several publication trends that are similar to those identified by Rodriguez et al.²⁰ In both reviews, the most common intervention type was related to chewing and swallowing. Both reviews also identified relatively few interventional studies with interventions focused on speech and voice. Only 1 study examining a speech intervention was identified in the Rodriguez review,²⁰ and only 5 such studies were identified in our review. It is notable that the oldest of the speech and voice studies captured in our review was published in 2012, with the rest following in 2014-2015; this suggests that although focused attention on speech- and voice-related interventions in HNC rehabilitation has been limited to date, this may be an active growth area in HNC rehabilitation research.

Study limitations

Our review had several important limitations. First, we performed our search in only 3 databases, which may have limited the

number of publications we identified. However, our review identified nearly the same number of interventional studies, despite stricter classification criteria, as the Rodríguez review,²⁰ which searched 6 databases; our review also had fewer duplicates (27 vs 188), suggesting an efficient search strategy. Second, our first 2 rounds of review only examined the title, keywords, and abstract, so additional relevant studies may have been missed. This is a known limitation of the scoping review methodology in general. Additionally, the classification of authors' primary credential was limited by the information that was provided in the publication itself, or in a general online search for the author; as such, we could not identify all first authors' credentials. The identification of physician-authors' sub-specialization was beyond the scope of this review, thus limiting our ability to definitively determine the rate of physiatrist participation in HNC rehabilitation research. Further, journal categorization (surgical, rehabilitation, etc) was limited by the information available in the purpose statement listed on the journal website. Finally, our review did not collect information about the specific outcome measures used in the studies, but rather focused on broad categories using the ICF model. More information about the specific measures that are commonly used would be useful for future study design.

Conclusions

Although the literature base in HNC rehabilitation is growing, many gaps in the literature remain. More prospective studies in multidisciplinary domains across the cancer care continuum are needed. There is particular need for controlled interventional studies and more robust prospective observational studies. Studies in pretreatment and survivorship populations, as well as those in inpatient settings, are also needed. It is our view that a more robust evidence base must be established before rehabilitation practice guidelines can be developed and implemented to manage the rehabilitation needs of HNC survivors across the cancer care continuum. Future studies should also expand beyond physical impairment to evaluate and treat clinically relevant activity limitations and participation restrictions with a goal of demonstrating the value of rehabilitation in HNC. Such studies may include cost-benefit analysis and patient-reported outcomes. Physiatrists and other rehabilitation professionals have an important role in the design and implementation of future HNC rehabilitation research.

Suppliers

- a. REDCap; Vanderbilt University.
- b. Excel, version 16.12; Microsoft.

Keywords

Cancer; Head; Neck; Neoplasm; Rehabilitation

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