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A review of the searchable web-based repository of papers published reporting quality of life in head and neck cancer by means of questionnaires: (HaNDLE-on-QoL)

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Keywords

Head and Neck Cancer; Quality of life; questionnaires; Patient Reported Outcomes; Review

Abstract

The importance of patient reported outcomes following head and neck cancer (HNC) is evident by the increasing number of papers in this area. It is challenging to keep up to date and readily access relevant papers. HaNDLE-on-QoL is a website resource and a repository of abstracts that have used patient completed questionnaires to report on ‘quality of life’ (QOL) following head and neck cancer. The site has a search engine by paper title, first author, year of publication, words used in the abstract, site of cancer, study design, and questionnaires used. The aim of this paper is to summarise the content of Handel on QOL. In May 2017, the website was searched by the criteria above. The site had 1498 papers. Publication numbers have increased over time from 1982 to present day, with 150 in 2015 and 185 in 2016. There is a range of sites but most are studies combine head and neck subsites (871), with 180 specifically oral and 109 focusing solely on larynx. There were 149 review articles. The commonest topics were swallowing (353), speech (299), pain (292), emotional (226), and depression (193). Most papers were on functional or predictors of HRQOL, however 98 were either clinical trials or RCT. The site has over 250 different questionnaires, commonest were The European Organization for Research and Treatment of Cancer -C30 (EORTC-C30) (369), The European Organization for Research and Treatment of Cancer –Head and Neck 35 (EORTC H&N35) (353), and the University of Washington Quality of life (UW-QOL) (276). HaNDLE-on-QoL highlights the complexity of QOL following HNC and the diversity and range of studies. It serves as a useful reference point for those involved in clinical practice or research.

Introduction

Over the past three decades Health Related Quality of Life (HRQOL) has become a significant outcome measure for cancer patients. This aspect of patients response now forms part of MDT guidelines ¹. Searching for Head and Neck HRQOL outcomes has previously been time consuming and cumbersome. Using standard search engines such as PubMed, OVID, or Google scholar gives large numbers of results, many of which are not relevant. Often such searches identify non-head and neck sites, non-cancer, and studies that do not report HRQOL using questionnaires. A lot of hand searching is required in order to identify pertinent articles.

Relating to HNC alone, a PubMed search returns over 5000 related papers. Unfiltered searches for outcome data relating to head and neck cancer gives too many inappropriate

papers, whilst restricted search terms risks the likelihood of missing relevant articles. Searching for “quality of life” at British Journal of Oral and Maxillofacial Surgery returns 756 papers. When this is directly searched in the article title/abstract/keyword this number falls, yielding 231 results of which 82 relate to head and neck cancer. A PubMed search for “quality of life outcomes head and neck cancer” returns 1161 results but intermixes general cancer and papers not relating to HRQOL specifically. Broader search engines give much greater numbers but less specificity – Google Scholar returns about 310,000 articles to the search criteria “quality of life outcomes head and neck cancer”

The interest in QOL relating to HNC is clear from the number of online access to one paper listing QOL papers from 2000-2005². This one paper was in the top 20 most downloaded articles from Science Direct in 2007.

The current published works utilise a plethora of questionnaires covering all aspects of HNC. Differentiating between HRQOL relating to different cancers has been a challenge for individuals and multidisciplinary teams alike.

Quality indicators within the NHS are increasingly using HRQOL outcomes to assess service delivery and treatment outcomes. The ability to rapidly research and compare unit outcomes is becoming greater importance to clinicians and managers alike.

Head and Neck Database Listing Evidence on Quality of Life (HaNDLE-on-QoL) has been developed to provide a unique searchable database of all papers on HNC related HRQOL outcomes that have specifically used patient self-completed questionnaires. All papers from 1982 to present are included in the website. The site is kept up to date and the number of studies increases as new ones are published and are added to the site.

Individual papers have been categorised according to: Title of publication, First author, Year of publication, Keywords, Subsite of H&N cohort, Study design, Theme, Type of study and Questionnaires used. The full reference and abstract is then linked. This has enabled the database to be readily accessible and the searchable criteria to be broad or narrow as desired.

Search results are displayed with accurate references and their full abstracts. They are ordered alphabetically according to paper title with 10 results per page and the total number of results displayed at the top of the page. The title then contains a clickable link to the abstract.

Searches can contain individual or a combination of criteria to narrow results. Keyword is a search of any word used in the title and abstract. This keyword facility allows the search

focus very specifically on a group of words such as studies reporting ‘intimacy, UW-QOL’, or conversely the results can be very broad if only one word is entered such as ‘swallowing’ and the larger number of results this yield allows the opportunity for personal ‘handsearching’.

It has been designed to be user friendly with fast and reliable results giving clear information of the papers on the database. There is a hyperlink on the website to highlight any database omissions to the updating team. The website works on desktop, tablet and smart phone.

As a new resource, available those interested in HRQOL outcomes following HNC, the aim of this paper is to summarise the content of HaNDLE-on-QOL.

Method

The website was systematically searched in May 2017 for the number of papers by; year of publication, common keywords, cohort and commonly used questionnaires. The results were then tabulated. All three authors interrogated the website separately, and then compared their findings. Agreement was reached by consensus if difference between the three was present.

Results

There were 1498 unique papers on the website. For years between 1982 and 1991 there are 27 papers; 1992 and 2001, 168 papers; 2002 to 2011, 611 papers and 2013 to 2017 (as of May 2017) 686 papers (figure 1).

Most studies reported on the broad site of ‘head and neck, 871 papers, combining oral, oropharyngeal and laryngeal subsites. However, the results show a large range of cohorts with 39 different classifications in total (table 1).

Not unexpectedly, there is a vast array of commonly used ‘keywords’ that could be used to search database. The most common key word relates to swallowing (353 papers), closely followed by speech (299 papers) (table 2). The most common keywords relate to function in addition to swallowing and speech, eating (191), dysphagia (153), xerostomia (120) but the psychological impact of head and neck cancer is represented by the large number of papers identified on the search terms emotion (226), psychological (199) and depression (193) and fear (27). Interestingly a keyword search on ‘information’ has relatively high frequency at 142 papers. The social impact of HNC is reflected in the number of papers on coping (69),

financial (36) and employment (29). Also, family and carers are hugely important as a determinant of HRQOL; papers with keywords social support (44), carer (11) and children (7) are represented. Given that comorbidity is a contributing factor to HRQOL it is a surprise that there were only 4 papers identified on this search term.

The most commonly used questionnaires are EORTC QLQ-C30, EORTC H&N 35 and UW-QOL. These account for almost two-thirds of all HRQOL papers (978/1498 in total) (table 3). Head and Neck cancer specific questionnaires again make up almost two-thirds of the total used but general cancer questionnaires remain the most prevalent in total (table 4).

As expected the most common type of paper relates to Questionnaire (n=1368) (table 5). Also prevalent are review papers making up 147 of the total.

When interrogated by theme the database shows the most papers relating to Function (n=637) (table 6). Only a small number are randomised control trials (n=17)

Discussion

The increase in numbers of HNC related HRQOL papers over the past 15 years has been dramatic. In 2002, 32 papers were published in this field, rising to 185 in 2016. Increased research has been driven by the value of HRQOL outcomes in individual and multidisciplinary clinical decisions. The benefit of HRQOL outcomes relating to treatment planning, protocols and follow up has been included to multidisciplinary protocols¹. The increase in appreciation of the importance of HRQOL and utilisation as outcome data has influenced the volume of research in this area

The data presented here is the first time the content of Handle-on-Qol has been summarised. It is not an attempt to critique the papers on the database or draw conclusions on the quality of papers, nor to report the comprehensiveness of the website in including all HRQOL papers reporting HRQOL using a questionnaire. The data was extracted by the authors and cross checked and consensus agreed for any discrepancies. The analysis of the website involves a moderate number of search terms for keywords and searches on additional terms can be performed by readers of this article. This study does not attempt to report the ease of use of the website. Reviews for HRQOL outcomes have been undertaken previously³ and the purpose of this study is to assess the HaNDLE-on-Qol searchable database only. The data

presented here pertains only to papers on the website and is not an attempt to summarise data from other sources such as PubMed or internet searches.

Rogers et al 2016 summarised the available papers relating to HNC related HRQOL outcomes between 2006-2013, identifying 572 papers³. This paper involved a relatively complex search process and concentrated on specific outcomes of the papers found. This analysis incorporates a much wider data range and more comprehensive searchable database outcomes.

This analysis shows that the predominance of research relates to primary functional issues e.g. swallowing, speech, pain. Indirect effects (e.g. emotional, socioeconomic) remain less fully explored currently. We would expect more clinical trials to be published in the future in this area where the primary outcome is HRQOL.

The use of multiple questionnaire types shows a possible lack of coordination of some research types which could be streamlined with improved access to similar studies and questionnaires. Having all this in one website should aim to align future research.

Clearly presented in this is data is the rapid increase in the number of papers on the database year on year. This will require regular updating of the database as new papers are published. A team approach to achieve will be essential in achieving this, also, if there are any papers that any person feels has been missed from the database, please let the site know.

For copyright reasons, the website only contains abstracts and does not have the full paper. Having the papers readily available would help those colleagues who perhaps are not linked to a university institution and might find it hard to get full pdfs.

Handle-on-QOL has distinct advantages over the traditional review article as the delay in publication means that in a review paper, new papers can emerge during the publication process and after publication. Handle-on-QOL is readily updatable and easy to accessible for current literature. It will prove to be an invaluable resource to future clinical and research development.

Conclusion

HaNDLE-on-QoL provides a useful resource for healthcare professionals from different backgrounds to keep up to date with past and emerging papers on HRQOL following HNC.

The ability to accurately and rapidly search HRQOL research should allow improved patient care and better outcomes with clinicians being able to readily consult the literature and identify areas for further research or evaluation. Being able to readily access data for all members of the MDT will provide a greater understanding and knowledge of HRQOL outcomes and their impact on patient centred care.

This database will also greatly benefit the research fraternity, helping with trial design and referencing. It will also assist in good quality clinical governance including clinical audit and service evaluations. The ability to rapidly and accurately access specific abstracts relating to specific criteria will enable multidisciplinary teams to evaluate their practice against the available body of research.

The current website holding 1498 papers and has shown a dramatic increase in the inclusion of HRQOL following HNC as a study aim of outcome. The range of subsites evaluated for HRQOL is comprehensive and the scope of issues evaluated substantial.

Conflict of interest statement

We have no conflicts of interest however Handle-on-QOL was developed by one of the authors (SNR).

Ethics statement/confirmation of patient's permission

The analysis of the website resource did not require ethical approval

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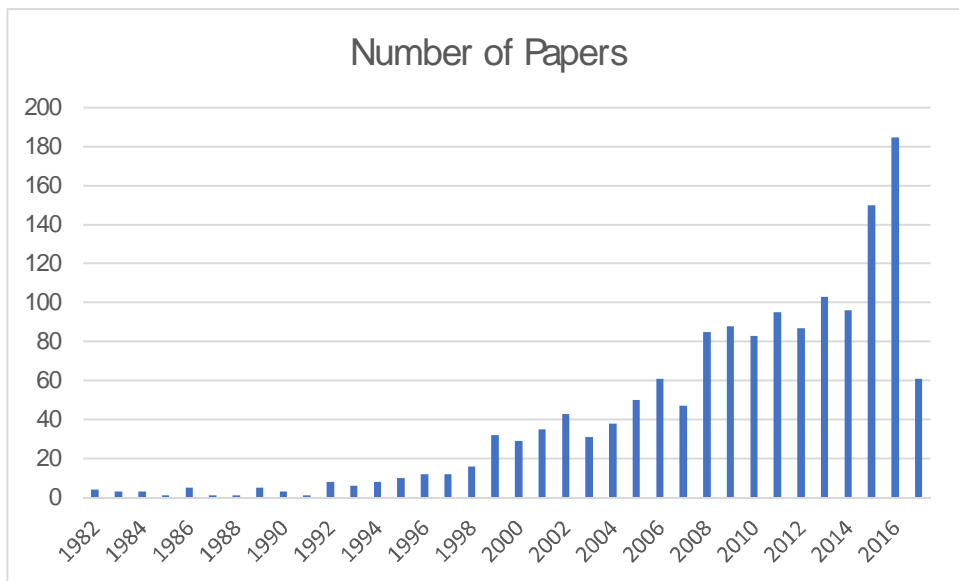


Figure 1 – Total number of papers per year

Table 1: Number of papers by site

Head and Neck	871
Oral	180

Larynx	109
Others	95
Review	51
Laryngectomy	46
Nasopharynx	41
Thyroid	28
Hypopharynx	22
Tongue	17
Oral and Oropharynx	15
Glottic	13
Maxilla	13
Mandible	12
Parotid	10
Neck	9
Pharynx	9
Recurrent	9
Sinuses	7
Stage 3	7
Stage 4	7
Base of Tongue	5
Pharyngolarynx	5
Supraglottic	3
Failed (Deep x-ray therapy) DXT	2
Maxillary Sinus	2
Rhinectomy	2

Tongue Base	2
Alveolus	1
Bilateral Neck nodes	1
Buccal Sulcus	1
Head and Neck – Vocal nerve palsy patients	1
Lymphoma of Waldeyers Ring	1
Oral (maxillary defects)	1
Pyriform Sinus	1
Soft Palate	1
Tonsillar	1
Total Glossectomy	1
Vestibular Schwannoma	1

Table 2: Common Key words

Swallowing	353
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Speech	299
Pain	292
Emotion	226
Psychological	199
Depression	193
Eating	191
Anxiety	163
Dysphagia	153
Information	142
Xerostomia	120
Diet	104
Fatigue	98
Nutrition	95
Shoulder	78
Coping	69
Mood	57
Alcohol	48
Sexual	44
Social Support	44
Disfigurement	41
Sociodemographic	39
Financial	36
Gastrostomy	31
Trismus	31
Employment	29

Fear	27
Body Image	18
Esteem	15
Neurotic	13
Percutaneous gastrostomy (PEG)	13
Carer	11
Intimacy	11
Personality	11
Optimism	9
Isolation	8
Children	7
Dental Status	5
Co-morbidity	4
Retirement	2
Poor sleep	1

Table 3: Commonly Used Questionnaires

The European Organization for Research and Treatment of Cancer -C30 (EORTC-C30)	369
The European Organization for Research and Treatment of Cancer Head and neck-35 (EORTCH&N 35)	333
University of Washington Quality of life (UW-QOL)	276
Hospital Anxiety and Depression Scale (HADS)	85
Functional Assessment of Cancer Therapy- Head and Neck (FACT-H&N)	77
Head and Neck Quality of Life (HNQOL)	25
Swallowing Quality of Life questionnaire (SWAL-QOL)	22

Table 4: Common Questionnaires by type

General	EuroQol-5D (EQ-5d)	7
General Cancer	EORTC C30	369
	Functional Assessment of Cancer Therapy: General (FACT-G)	41
Head and Neck Cancer Specific	EORTC H&N 35	353
	UW-QOL	276
	FACT H&N	77
Head and Neck Cancer Function Specific	The M. D. Anderson Dysphagia Inventory (Dysphagia MDADI)	62
	The voice-related quality of life (V-RQOL) measure	15
	The Liverpool Oral Rehabilitation Questionnaire (LORQ)	7
	Neck Dissection Impairment Index (NDII)	7
	SYDNEY Swallow questionnaire (SSQ)	1
Other	HADS	85
	Derriford Appearance Scale 24 (DAS24)	2

Table 5: Type of HRQOLassessment

Questionnaire	1368
Review	149
Interview	37
Non-Validated	11

Table 6: Numbers by Theme

Functional	637
Predictor	544
Questionnaire Development and validation	143
Review and Editorial	141
Clinical Trial	81
Randomised Clinical Trial	17
Case Control	2