



Review of HaNDLE-on-QoL: a database of published papers that use questionnaires to report quality of life in patients with cancer of the head and neck

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Abstract

HaNDLE-on-QoL (Head And Neck Database Listing Evidence on QoL) is a searchable database that comprises abstracts of papers that have used questionnaires to report on quality of life (QoL) in patients with cancer of the head and neck. It can be searched by title, first author, year of publication, words used in the abstract, site of cancer, study design, and questionnaires used. The aim of this paper was to summarise its contents. In May 2017 we searched the website using the criteria above. It contained 1498 papers (including 149 reviews), and the number is increasing each year. Most studies concerned a combination of subsites in the head and neck ($n = 871$); 180 focused specifically on oral sites, and 109 on the larynx. The commonest topics were swallowing ($n = 353$), speech ($n = 299$), pain ($n = 292$), emotions ($n = 226$), and depression ($n = 193$). Nearly all the papers concerned function or predictors of health-related QoL (HRQoL), but 98 were clinical or randomised controlled trials. The site included over 250 questionnaires of which the most common were the European Organisation for Research and Treatment of Cancer C30 (EORTC-C30, $n = 369$), the EORTC-head and neck 35 (EORTC H&N35, $n = 353$), and the University of Washington Quality of Life (UWQoL) ($n = 276$). HaNDLE-on-QoL highlights the complexity of QoL after treatment and the diversity and range of the studies. It is a useful point of reference for those involved in clinical practice or research.

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Introduction

Over the past three decades, health-related quality of life (HRQoL) has become an important outcome measure for patients with cancer, and now it forms part of United King-

dom national multidisciplinary guidelines.¹ Searching for HRQoL outcomes in patients with cancer of the head and neck has previously been time-consuming and cumbersome, with standard search engines such as PubMed, OVID, or Google Scholar giving large numbers of results, many of which are not relevant.

A search for “head and neck cancer” in PubMed returned over 5000 papers. Unfiltered searches for outcome data on head and neck cancer find too many inappropriate papers, while relevant articles can be missed if the search is more restricted. A search for “quality of life” in the British Journal

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of Oral and Maxillofacial Surgery returned 756 papers. When the title, abstract, or keyword was used the number fell to 231, of which 82 related to cancer of the head and neck. A search for “quality of life outcomes head and neck cancer” on PubMed found 1161 results, but these included cancer generally and papers not specifically about HRQoL. Broader search engines give many more but are less specific, and a search for “quality of life outcomes head and neck cancer” on Google Scholar returned about 310 000 articles.

There is clearly much interest in the QoL of patients with cancer of the head and neck, and a paper that listed QoL papers from 2000–2005² was one of the 20 most downloaded articles from Science Direct in 2007.

Current published studies use many different questionnaires that cover all aspects of the disease, and previously it has been difficult to differentiate between HRQoL in different cancers. In the NHS, HRQoL outcomes are increasingly being used to assess how well services are being delivered and outcomes of treatment, so the ability to research and compare outcomes rapidly is becoming more and more important to clinicians and managers alike.

HaNDLE-on-QoL (Head And Neck Database Listing Evidence on Quality of Life) was developed to provide a unique searchable database of all relevant papers that have used patient-reported questionnaires to report HRQoL outcomes.³ It comprises all papers from 1982 to the present and is constantly being updated.

Studies have been categorised according to title, first author, year of publication, keywords, subsite, design or type, theme, and questionnaires used. The full reference and abstract are then linked. This makes the database readily accessible and the searchable criteria can be as broad or narrow as desired.

Search results are displayed with accurate references and their full abstracts. They are listed alphabetically by title with 10 results on each page and the total number at the top. The title contains a link to the abstract. The keyword facility

enables a search of any word in the title or abstract. This can be focused, for example, on a group of words, or broad, for example, using only one word only to find a larger number of results that can be searched by hand.

The site is easy to use on desktop computer, tablet, or smartphone, and the fast and reliable results give clear information. There is a hyperlink that can be used to highlight omissions to the updating team.

As HaNDLE-on-QoL is a new resource, the aim of this paper is to summarise its contents.

Method

In May 2017 we systematically searched the website for papers by year of publication, common keywords, cohort, and commonly-used questionnaires, then tabulated the results. All three authors searched it separately, and then compared their findings. Agreement was reached by consensus if there was a difference of opinion.

Results

There were 1498 unique papers on the website. Fig. 1 shows the number/year. Most studies reported on the “head and neck” (n = 871), which included oral, oropharyngeal, and laryngeal subsites. However, in total, there were 38 different classifications (Table 1).

The results of searches using common keywords such as “swallowing” or “speech” are shown in Table 2, and many also relate to function. The impact of the disease on patients’ lives is reflected by the large number of papers found when searching for “emotion” (n = 226), “psychological” (n = 199), “depression” (n = 193), “fear” (n = 27), “coping” (n = 69), “financial matters” (n = 36), and “employment” (n = 29).

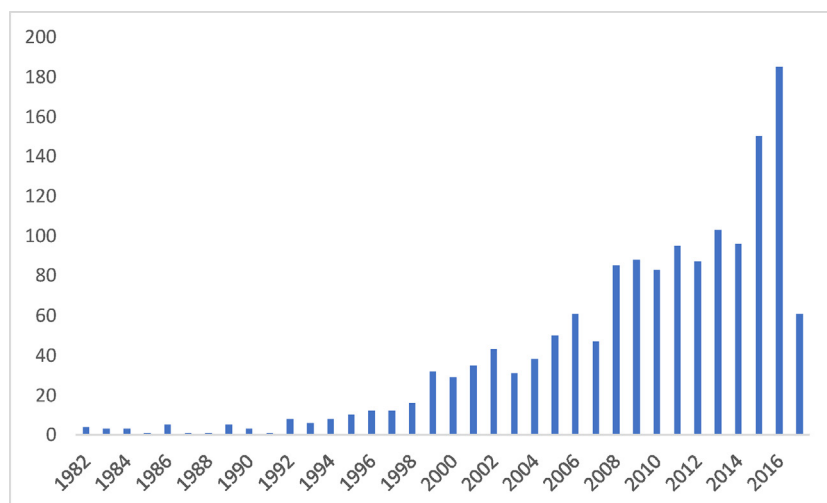


Fig. 1. Total number of papers/year.

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