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The internet for self-diagnosis and prognostication in ALS

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Abstract

Persons with ALS, and those close to them, may use the internet to explore symptoms prior to formal diagnosis, and as a source of information about prognosis and treatment thereafter. We used an internet search engine to rank the sensitivity of a variety of symptom search terms a patient might use for the diagnosis of ALS/MND. We also studied search engine responses to questions about life expectancy and possible 'cure'. An internet search engine in relation to ALS currently lacks sensitivity, and results varied greatly with only minor differences in the search terms used. The prognostic information did not reflect the inherent heterogeneity. Results in relation to 'cure' were misleading and may promulgate false hopes. There is a need to guide those with ALS (and particularly their children) to sources of reliable web-based information in addition to open discussion.

Keywords

Internet; search engine; Google; online; web

Introduction

The public awareness of ALS/MND is limited (1), and a significant delay between onset of symptoms and diagnosis persists. Reduction of the latter will be important if future therapeutic agents are 'pathostatic' rather than curative, and thus more effective applied in the earliest stages of low disability. The internet has increased the accessibility of medical information, and use of search engines may be an activity through which patients (or family members by proxy) first become aware of the possibility of ALS, or make erroneous diagnoses. ALS is characterized by its prognostic heterogeneity and generalized information gleaned from the internet after diagnosis, including the misperception of effective treatments, may have profound implications for the management of patient expectation subsequently. We sought to study what ALS patients experiencing their first symptoms might in theory glean from using a search engine to self-diagnose and then, post-diagnosis, to self-prognosticate.

Methods

We reviewed the results generated by the search engine Google™ for common symptoms likely to be encountered by ALS patients prior to diagnosis, and ranked them in order of

sensitivity. Grammatical variations were also entered to examine whether this materially affected the results, e.g. 'slurred' versus 'slurring'. We observed the number of search results before the first one containing either 'Motor Neurone Disease' or 'Amyotrophic Lateral Sclerosis' in the title of the search result, the two-line summary or the webpage itself, up to the 400th result. We then also studied the range quoted using the search term 'life expectancy in motor neurone disease (or amyotrophic lateral sclerosis)'. Finally, we searched using the terms 'cure for motor neurone disease (or amyotrophic lateral sclerosis)'.

Results

Results for the symptom search terms are shown in Table I. Of the first 30 results for 'life expectancy', 19 (63%) offered an estimate visible in the summary lines for the webpage. The most common result (53%) was 24–60 months (mean 41 months, range 6–60 months), but there was notable variability in whether this was listed as survival from symptom onset or diagnosis. One site reported that ALS patients 'may have a normal life span'. There were 809,000 results returned in a search of the term 'cure' for MND, and 2,050,000 for ALS. Of the first 30, one-third and one-quarter, respectively, mentioned specifically that there was 'no cure'. Three sites (10%) mentioned 'zebrafish' in relation to a cure. Sponsored links listed separately on the right-hand side of the results pages offered 'herbal' cures and 'stem cell therapy'.

Discussion

The number of search 'hits' taken to reach a webpage involving ALS/MND was highly variable and slight variations in the search term produced markedly different results. In those with initially lower limb symptoms, the terms 'tripping up' (fourth hit), 'stumbling' (317th hit), 'trip up' (>400th hit), and 'tripping' (>400th hit) produced markedly variable results. We do not believe this is an issue unique to Google™, and it is also likely that there will be variation between languages (where synonyms may differ), and possibly in relation to country of web access (neither of which was explored in this study). Concerning lack of specificity, we observed search terms such as 'drooling', while not offering ALS/MND as a differential diagnosis within the 400th hit limit, produced several differential diagnoses, including cerebral palsy, Parkinson's disease and Alzheimer's disease. We conclude that this probably reflects publication frequency bias. It is noteworthy that searches relating to fasciculations ('muscle twitching') were among the most sensitive, while having a low specificity in isolation for ALS, and frequent among the 'worried but well' in our experience. There is also an issue of improving the level of suspicion for ALS among primary care physicians, where we have previously noted inappropriate referral of half of ALS patients with bulbar-onset symptoms (2).

A previous generic study of the usefulness of search engines in making a neurological diagnosis confirms that they offer poor sensitivity and specificity to the lay individual (3). We noted a specific report in relation to an erroneous self-diagnosis of ALS (4). When utilized with the Bayesian logic that is naturally developed as part of a medical degree, search engines do have significant added value for the physician, however, and may have a particular benefit in linking disparate symptoms together (5).

We observed information on life expectancy to be blunt and untailored to an individual's phenotype. As well as patients, this has significant implications for inquisitive family members, particularly children who may be searching for an explanation for a parent's symptoms soon after onset, often without their knowledge, and sometimes at a young age. The internet's presentation of unfiltered information means that false hope about perceived cures remains a particular concern, and can in theory lead to a breakdown in confidence

between patient and clinician if such ‘cures’ are dismissed or not fully addressed. Another issue is misinterpretation of valid information. Our searches revealed that ‘zebrafish’ might easily be interpreted to mean a nutritional supplement to ‘cure’ ALS, rather than appreciating its true role as a model of the disease. A recent neurologist-led initiative ALSUntangled is specifically trying to meet the needs of ALS patients in relation to unproven treatments that appear on the internet (6). Disease-based online patient communities such as PatientsLikeMe.comTM may also have an increasing role to play in allowing patients to share and assimilate information, and have already been used to explore patient attitudes to clinical trial involvement (7).

Few would doubt the overwhelming net benefit of the internet, but we suggest that our confirmation of some of the easily recognized limitations should prompt a more proactive approach to help patients and their carers navigate to reliable sources of information online, rather than advice to “avoid the internet” (which several of our patients report having been told by previous clinicians). We suggest that the issue of providing adequate information to children warrants particular focus. As a reminder of the work still to do more generally, it is noteworthy that in a study of PLS patients a larger proportion sought information about their condition from the internet (68%) than from their physician (52%) (8).

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Table I

Symptoms entered into the internet search engine in ascending order according to the number of links prior to the one stating MND or ALS as a possible diagnosis.

Search term	Number of results before ALS/MND mentioned as differential
tripping up	4
slurred speech	8
muscle twitching	13
muscle twitches	20
muscle twitch	22
slurring speech	23
difficulty walking	25
causes excess saliva	43
weak hands	92
excess saliva	104
excess drooling	105
muscle cramp	150
stumbling	317
problems walking	352
weak grip	>400
trip up	>400
tripping	>400
drooling	>400
problems running	>400
difficulty running	>400