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Evaluation of the quality and health literacy demand of online renal diet information

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Evaluation of the quality and health literacy demand of online renal diet information

Abstract

Background: Dietary modification is critical in the self-management of chronic kidney disease. The present study describes the accuracy, quality and health literacy demand of renal diet information for adults with kidney disease obtained from the Internet and YouTube (www.youtube.com).

Methods: A comprehensive content analysis was undertaken in April and July 2015 of 254 eligible websites and 161 YouTube videos. The accuracy of the renal diet information was evaluated by comparing the key messages with relevant evidence-based guidelines for the dietary management of people with kidney disease. The DISCERN tool (www.discern.org.uk) was used to evaluate the quality of the material. Health literacy demand was evaluated using the Patient Education Material Assessment Tool (www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/index.html) and seven validated readability calculators.

Results: The most frequent renal diet topic found online was generic dietary information for people with chronic kidney disease. The proportion of renal diet information obtained from websites that was accurate was 73%. However, this information was mostly of poor quality with extensive shortcomings, difficult to action and written with a high health literacy demand. By contrast, renal diet information available from YouTube was highly understandable and actionable, although only 18% of the videos were accurate, and a large proportion were of poor quality with extensive shortcomings. The most frequent authors of accurate, good quality, understandable, material were government bodies, dietitians, academic institutions and medical organisations.

Conclusions: Renal diet information found online that is written by government bodies, dietitians, academic institutions and medical organisations is recommended. Further work is required to improve the quality and, most importantly, the actionability of renal diet information found online.

Disciplines

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Keywords: Chronic kidney disease; consumer health information; diet therapy; health literacy; readability; internet.

Contribution of authors: KL: study design, acquisition, analysis and interpretation of the data. JM and KM: study design, and interpretation of the data. AK and LM: study design, acquisition, analysis of the data. All authors participated in the drafting and approval of the final manuscript submitted for publication.

Abstract

Background: Dietary modification is critical in the self-management of chronic kidney disease. This study evaluated the quality and health literacy demand of renal diet information for adults with kidney disease obtained from the Internet and YouTube.

Methods: A comprehensive content analysis was undertaken of information available on the internet and YouTube. Online renal diet information was compared to evidence based guidelines for the dietary management of people with kidney disease. The quality and health literacy demand of the information was evaluated using the DISCERN and PEMAT tools and readability calculators.

Results: The most common renal diet topic found online was generic dietary information for people with CKD. Only 73% (n=254 websites) of the renal diet information obtained from the internet was consistent with evidence based guidelines. However, the information was mostly of poor quality with extensive shortcomings, difficult to action and written with a high health literacy demand. In contrast, renal diet information available from YouTube (n=161 videos) was highly understandable and actionable, but only 18% of the videos were evidence based; and a large proportion were of poor quality with extensive shortcomings. The main authors of good quality, understandable, evidence based material were dietitians, medical organisations, academic institutions and governmental bodies.

Conclusions: Renal diet information found online that is written by dietitians, medical organisations, academic institutions or governmental bodies are recommended because these are likely to be evidence based. Further work is required to improve the quality and improve the actionability of renal diet information found online.

Keywords: Chronic kidney disease; consumer health information; diet therapy; health literacy; readability; internet.

INTRODUCTION

A key component of the self-management of chronic kidney disease (CKD) is adherence to the appropriate dietary prescription ^(1; 2; 3). However, the dietary prescription for the management of CKD is considered complex and challenging for many patients ⁽⁴⁾. Patients report feeling ‘bewildered’ about the renal diet and often find it difficult to follow ⁽⁵⁾. This is further compounded by the nature of the diet prescription, which becomes more complex and changes as CKD progresses ⁽³⁾.

Adherence to the diet prescription is not only compromised by its complexity but also by other factors which include inadequate health literacy and cognitive impairment. These factors are common in patients with advanced kidney disease ^(6; 7; 8; 9), and they can negatively impact upon their ability to understand, apply and adhere to their diet prescription. Adherence to the renal diet may be compromised further, if patients receive conflicting messages about the renal diet from the nephrology team, the dietitian, and from their own sense of correct food choices ^(4; 10).

In an attempt to deal with these conflicting messages, it is likely that patients (or their carers) will use readily accessible online information sources such as the internet ^(11; 12; 13), or the most popular online video sharing website, YouTube ⁽¹⁴⁾ to seek further information about their renal diet. In fact, user statistics from 2007 indicated that, at that time, approximately 60% of adults with end stage kidney disease had conducted online searches for health information ⁽¹²⁾. However, the exact proportion of these searches that were related to the renal diet is unknown.

Only a small number of studies have evaluated online information for people with chronic kidney disease (CKD). The results of these studies indicate that online health information is frequently written at a level that exceeds the health literacy skills of patients with CKD ^(15; 16; 17). A study which evaluated dialysis related YouTube videos, found the videos to be misleading and/or inaccurate ⁽¹⁸⁾. Given that these studies did not specifically evaluate the quality or health literacy demand of renal diet information, the aims of this study, were (i) to describe the main types of online renal diet information (that is, information available on the internet and YouTube) (ii) to determine the proportion of online renal diet information that was evidence based, and (iii) to describe the quality and health literacy demand of online renal diet information.

METHODS

This research was an exploratory study using a combination of desk based methods used in previous content analysis or health literacy demand studies ^(16; 18; 19; 20; 21; 22). As a result, ethics approval was not required.

A list of renal diet related search terms were constructed to search the internet and YouTube (Table 1). These search terms were constructed using professional clinical judgement and informal feedback obtained from individuals with chronic kidney disease (n=3). Search terms were entered into the three most popular search engines used in Australia: Google, Yahoo and Bing ⁽²³⁾. Potential websites for analysis were restricted to the first seven pages of results for each search term in accordance with recent Internet user behaviour studies ⁽²⁴⁾. An initial pilot search of YouTube using the first two search term combinations yielded more than 97000 potential videos for evaluation. Therefore, potential videos for analysis were restricted

to the first seven pages of results on YouTube, and the search was confined to the first two search terms as shown in Table 1.

Exclusion criteria included those websites and YouTube videos: (i) that were not in English; (ii) were not related to kidney disease in humans; (iii) did not provide dietary information for people with kidney disease; (iv) access was prohibited due to password protection; (v) information retrieved from websites was limited to less than 150 words or (vi) the video was not audible.

Information about the renal diet retrieved from the internet or YouTube was categorised into one of nine renal diet topic categories (Table 1). Similarly, the authors of the renal diet information were categorised into one of ten categories, with two additional unique author categories of 'unclear sources' and 'patient testimonials' (Table 1) required for categorisation of YouTube videos based on previous research ⁽¹⁸⁾.

The renal diet information retrieved from the internet and YouTube was evaluated by an experienced renal dietitian and first author (KL). The key messages outlined in the retrieved information were then compared to evidence based guidelines for the dietary management of kidney disease ^(1; 3; 25; 26; 27; 28). Information was then rated as either being 'evidence based' or 'non-evidence based' according to whether or not they complied with the guidelines.

Evaluation of the quality renal diet information

The quality of the renal diet information obtained was evaluated using the DISCERN appraisal process and related tool ⁽²⁹⁾. The DISCERN tool was originally developed to enable consumers of health information to evaluate the quality of written health information ⁽²⁹⁾. The

tool allows users to evaluate the quality of the information by reviewing whether the sources of evidence within the health information are explicit; the material is current, unbiased and reliable. Using this tool, the overall quality of the information is scored using a 5 point Likert scale. An overall DISCERN quality rating score of (2) or below indicates the material is of poor quality and has serious or extensive shortcomings; a rating of (3) indicates the material is of fair quality with potentially important but not serious shortcomings; and a rating of (4) or above indicates the material has minimal shortcomings and is of good quality⁽²⁹⁾. In this study, the proportion of materials considered poor, fair, and good quality are reported.

Evaluation of the health literacy demand of renal diet information

The Patient Education Materials Assessment Tool (PEMAT)⁽³⁰⁾ was used to evaluate the understandability and actionability of the renal diet information obtained, which is referred to as the ‘health literacy’ demand. According to the authors of the tool, ‘understandability’ refers to health information that is written in a manner that can be understood by health consumers from diverse backgrounds and with varying levels of health literacy⁽³⁰⁾.

‘Actionability’ refers to health information that is written in a manner that enables health consumers to easily identify what they need to do, based on the information presented⁽³⁰⁾.

The PEMAT scores materials on a scale of 0-100, with a score of 100% indicating higher ‘understandability’ and ‘actionability’, respectively. A score of greater than 70% has been set by the authors of the tool as indicative of material that is understandable and actionable⁽³⁰⁾.

There are two versions of the PEMAT⁽³⁰⁾: a version for written information which includes 17 criteria for assessing ‘understandability’ and seven criteria for assessing the ‘actionability’; and an audio-visual version of the PEMAT⁽³⁰⁾ which includes 13 criteria for assessing ‘understandability’ and four criteria assessing ‘actionability’. Each criteria in both versions of the PEMAT is evaluated in a binary fashion as either agree or disagree.

The literacy demand (readability) of the written diet information retrieved from the internet in this study, was assessed by cutting and pasting written material into an online readability calculator (<http://www.readabilityformulas.com/free-readability-formula-tests.php>.)⁽³¹⁾. This calculator was used to obtain an average of the estimated reading age and grade level required to read the written material. The reading formulas used in the online calculator include: the Flesch Reading Ease formula ⁽³²⁾; the Flesch Kincaid Grade Level ⁽³³⁾, the Gunning FOG formula ⁽³⁴⁾; the SMOG Index ⁽³⁵⁾; the Coleman-Liau Index ; the Automated Readability Index ⁽³⁶⁾ and the Linsear Write Formula ⁽³⁷⁾.

Statistical analysis

All data was analysed using SPSS Version 21 software (SPSS Inc., Chicago, Illinois, USA). Normality was assessed using the Shapiro Wilk Test, with the data reported as median and interquartile range (IQR). Wilcoxon Rank Sum or Kruskal Wallis tests were used to compare scores between groups (such as understandability and actionability between author types or between the internet and YouTube). A p value of $p < 0.05$ was considered statistically significant.

RESULTS

Internet searches were conducted on the 20th April 2015 and YouTube searches on 2nd July 2015. A total of 1125 internet websites and 280 YouTube videos were identified using the keyword searches. After exclusion of duplicates and ineligible sites or videos, a total of 254 websites (Figure 1) and 161 YouTube videos (Figure 2) were eligible for analysis.

The most common renal diet topics found on the internet and YouTube are shown in Table 2. Diet for CKD was the most common type of renal diet information found on both the internet and YouTube (n=101, 39.8% and n=132, 82.0% respectively). Generic diet information for dialysis was the second most frequent topic retrieved from the internet (n=46, 18.1%), whereas the miscellaneous category was the second most frequent renal diet information topic retrieved from YouTube (n=16, 9.9%). Diet information for each of the following: kidney stones, polycystic kidney disease, predialysis, peritoneal dialysis and hemodialysis made up less than ten percent of the total number of diet topics on the internet. Each of these same topics were extremely limited (less than 5 %) or non-existent on YouTube.

Table 2 indicates that the almost three quarters of the information obtained from internet sites (n=186; 73.2 %) was evidence based. In contrast, less than one fifth of the YouTube videos (n=29; 18.0%) were considered to be evidence based renal diet information. For the most common renal diet category ('Diet for CKD'), the majority of the information available on the internet was evidence based, (n=70; 69.3%), whereas the majority of the information for this same category on YouTube was non-evidence based (n=112; 84.8%). In addition, the majority of the online diet information retrieved for people with Poly Cystic Kidney Disease (internet, n=14, 87.5%; YouTube, n=4, 66.7%) and Miscellaneous (internet, n=10, 58.8%; YouTube, n=12, 75%) was non-evidence based.

Table 3 highlights that the most frequent authors of internet based renal diet information were medical organisations (n=86, 33.9%; the majority of which was evidence based n=77, 89.5%); followed by commercial organisations (n=69, 27.2%; just over half of which was evidence based n=39, 56.5%) and naturopaths (n=25, 9.8%, the majority of which was non-evidence based n=18, 72.0%). In contrast, analysis of information obtained from YouTube

indicates that commercial organisations were the most frequent authors of renal diet information (n=119; 73.9%, most of which was non-evidence based n=111, 94.1%) and mainly reliant on two individuals (see Appendix 1). This was followed by unclear sources (n=9, 5.6%) and patient testimonials (n=9, 5.6%), both of which were primarily non-evidence based (n=9, 100% and n=7, 77.7% respectively). Notably, all diet information provided by academic, governmental and dietitian authors available on the internet was evidence based, whereas YouTube did not contain any videos from academic or governmental authors. However, the limited information available on YouTube that was authored dietitians (n=8, 5%) and patient support organisation (n=5, 3.1%) was all evidence based.

Approximately half of the diet information available on the internet (n=126, 49.6%) and YouTube (n=94, 58.4%) was of poor quality with extensive or serious shortcomings (Table 4). One quarter of the renal diet information retrieved from the internet was of good quality with minimal shortcomings (n=66, 26.0%). The majority of the good quality information was evidence based (n=65, 98.5%). Approximately one quarter of the internet based information was also found to be of fair quality (n=62, 24.4%), and again the majority of fair quality material was evidence based (n=61, 98.4%). In contrast, even though the majority of good quality material was evidence based (n=13, 68.4%), it constituted a very small proportion of renal diet information obtained from YouTube overall (n=19, 11.8 %). Just under one third (n=48, 29.8%) of the mainly non-evidence based (n=38) YouTube information was of fair quality.

Information obtained from websites was written at a median readability level of Grade 10 (IQR: 9-12), and for a median 14 year old reader (IQR: 14-17)(Table 4). This is considered to be a reading age of approximately 10th grade or a 14-15 year old high school student.

Readability levels of internet based information did not differ between evidence based and non-evidence based material. The understandability levels of the internet based information (75%; IQR: 50-87%) were significantly lower than that of the YouTube information (91%; IQR: 87.7-100%; $p < 0.0001$). Furthermore, the evidence based YouTube information was significantly more understandable (100%; IQR: 89.2-100%) than evidence based information on the internet (77%; IQR 59.8-92%; $p < 0.0001$). Similarly, the actionability scores of the internet based information (40%; IQR: 29-80%) and YouTube information (100%, IQR 66-100%) were significantly different ($p < 0.0001$), with the YouTube information being much more actionable (Table 4). Overall, the actionability scores were considered poor for evidence based material on the internet (50%; IQR 33-86%) and YouTube (67%; IQR 33-100%) and were not significantly different.

Table 5 contains further details of the health literacy demand of renal diet information obtained from the internet according to author type. Information authored by academic institutions, governmental bodies, dietitians and medical organisations all had understandability scores $> 70\%$ on the internet and YouTube. That is, the material was considered understandable⁽³⁰⁾. Material by all other author categories was considered to be more understandable if obtained from YouTube. The only author categories with acceptable actionability scores were governmental bodies (median actionability score internet information 83%, IQR: 67.7-100%) and dietitians (median actionability score of YouTube information 100%; IQR: 46.8-100%). Although the median actionability score for materials authored by dietitians on the internet was below the cut off of 70% (67%, IQR:38.3-100%) it was not significantly, different from the median actionability score of YouTube information authored by dietitians (100%; IQR: 46.8-100%).The YouTube actionability scores of renal diet information authored by commercial organisations and unclear sources were also high

(median actionability score, commercial organisations: 100%; IQR: 66-100%; and median actionability score, unclear sources: 100%; IQR: 100-100%;). However, as discussed previously, the proportion of evidence based information from these sources was low.

DISCUSSION

High quality, evidence based health information is an essential tool to educate patients about how to take a proactive role in the self-management of their health ^(38; 39). In this study, we found that the proportion of renal diet information obtained from the internet and YouTube that was considered to be of good quality, evidence based and highly understandable and actionable was very low. Furthermore, renal diet information from the internet and YouTube was dominated by generic information about the diet for CKD. Therefore, the results of this study suggest that health professionals should only refer patients to the internet or YouTube for renal diet information, if it is accompanied with explicit guidance on how to locate the relatively small number of appropriate high quality, evidence based materials.

The findings of this study regarding the quality of online renal diet information provide a useful contribution to the small body of content analysis literature in the area of nephrology. Our findings on readability are consistent with previous work on the readability levels of online CKD related material ^(16; 17; 40). However, our research extends previous work in the CKD context by evaluating the consistency of renal diet information with evidence based guidelines, and by analysing this material with respect to the important and emerging area of health information understandability and actionability ⁽⁴¹⁾. One of the key points from this study is that evidence based renal diet information on the internet is written at a readability level of approximately Grade 10. This is more than three levels above the readability levels

for health materials recommended by bodies such as the National Institute of Health ⁽⁴²⁾ and the Australian Clinical Excellence Commission ⁽⁴³⁾. Exceeding the minimum requirements for plain language health information means that patients (especially those with low health literacy), may not be able to comprehend or use the renal diet information found online to meet their needs ⁽⁴⁴⁾.

Health professionals often report that they lack confidence on how to instruct their patient's to search for appropriate information on the internet ^(45; 46). This is not surprising given the rapid rate of change of information found online. Recent scoping work on the information practices of patients with CKD has indicated that there are patients with CKD who are actively engaged and looking for CKD related information online ⁽⁴⁷⁾. This is often used as an adjunct to advice received from the health professional ^(39; 48). Health professionals are also often asked to contextualise or clarify online information found by carers of patients with CKD ^(49; 50). We have therefore constructed a summary of the characteristics of good quality, evidence based renal diet information (Table 6). This table has been developed using the results of this study, as well as frequently cited guidance on how to assess the quality of medical information on the internet ⁽⁵¹⁾. Table 6 could also be used to guide health professional discussions with patients regarding the features of appropriate renal diet information on the internet or YouTube.

One of the key issues relating to patient education materials relating to the renal diet available on the internet is the scarcity of good quality renal diet information that is both understandable and actionable. This has important implications for patient adherence. In this study, only academic institutions, governmental bodies, dietitians and medical organisations scored strongly in terms of understandability and only governmental bodies, scored well for

actionability. However actionable information is highly valued and preferred by patients with CKD ^(5; 10; 52). This suggests that more attention is required to the inclusion of simple, practical, actionable instructions (for example, including details on how to incorporate the renal diet into family and social occasions). This would theoretically enable all patients, not just those with inadequate health literacy or impaired cognition ^(53; 54) to adopt healthy renal diet behaviours ^(30; 55). Designing renal diet information that is actionable may also prevent patients from searching for alternative (and possibly incorrect) information, because the renal diet information they have obtained contains clear instructions on what to change. Designing more effective renal diet information that is both understandable and actionable could therefore increase patient knowledge, and address the key concerns of patients. This may well be an important part of improving renal diet adherence ⁽⁵⁶⁾.

A second key message about renal diet information online is that not all online information about the renal diet is evidence based. Therefore, renal diet information found online by patients may be contradictory to advice they have received from their health care team. This is problematic as it has been observed that when people encounter conflicting health information, substantial cognitive effort is required to process the contradictory information ⁽⁵⁷⁾, and this is believed to lead to errors in judgement ⁽⁵⁸⁾. As a result, we therefore suggest that patients look for renal diet information authored by dietitians, medical organisations, academic institutions or governmental bodies, as they were the most likely to be evidence based. Material from these organisations is preferred than material authored by commercial organisations, naturopaths or via patient testimonials, because in this study, they were found to be predominantly non-evidence based. The consequences of following renal diet advice that has been obtained from non-evidence based sources could be consumption of

inappropriate foods, or avoiding potentially suitable foods. This may result in reduced dietary variety and quality in an already limited diet.

The limitations of this study include the cross sectional nature. Information was also limited to information in the English language only, and non English material may be of a different quality. YouTube search terms were also limited to only two combinations for pragmatic reasons. It is also possible that the key word combinations used for searching may not reflect the internet searching practices of all people with kidney disease. Despite this, we believe the nature of the searches we conducted were comprehensive. We did not specifically exclude commercial organisations or other patient support organisations like previous content analysis studies ^(59; 60). This is because information from these sites may be used to inform the decisions and change the dietary or health behaviours of people with kidney disease ⁽⁶¹⁾; and as shown in this study, information from these sources makes up a substantial portion of the information to be found.

Future work should be directed to increasing the number of high quality, evidence based, renal diet information resources online. One topic area for immediate action would be renal diet information that clearly describes the type of dietary changes required for predialysis patients. Similarly, there is a paucity of evidence based information online for people with Poly Cystic Kidney Disease. Research that utilises the perspectives of patients with kidney disease regarding the preferred content and format of renal diet related information is also desirable. Further work investigating how patients with kidney disease make sense of, and implement complex renal diet related self-management advice is also required, and could be used to inform the design of future dietary self-management programs and health information.

This comprehensive study of online renal diet information has shown that renal diet information available online is often of poor quality, with variable levels of health literacy demand and is dominated by generic information for people with CKD. Web based searches that are directed to renal diet information authored by dietitians, medical organisations, academic institutions or governmental bodies are recommended because these are likely to be evidence based. Future work is required to improve the quality and reduce the health literacy demand of renal diet information online. Engaging with patients and carers about the preferred format and content is also suggested.

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