Online patient resources for deceased donor and live donor kidney recipients: a comparative analysis of readability

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Abstract

Background: The Internet has extensive resources for kidney transplantation recipients. Half of the population reads below a seventh-grade level. Previous studies showed that living donor recipients have higher health literacy rates compared with deceased donor recipients. There has been no study comparing the readability of online living donor recipient materials versus deceased donor recipient materials.

Methods: Analysis was performed using eight readability scales on the top 10 websites for live donor and deceased donor kidney transplantation. Analysis was performed through the Readability Studio Software. USA reading grade level was determined for each site.

Results: Overall, the mean reading level for the living donor materials was 12.54 (range 9.2–17) and for the deceased donor materials, 12.87 (range 8.7–17, P = 0.73), corresponding to a university level. None of the sites met the seventh-grade level recommended by the National Institute of Health.

Conclusions: The readability of online materials remains too high for the corresponding health literacy rates among patients requiring kidney transplantation. Specifically, the lower health literacy rates among deceased donor recipients does not mirror the readability of online materials provided at a university level. This may affect decision-making, contributing to a smaller proportion of patients of a lower socioeconomic status and those with poor English language skills pursuing live donor organs.

Key words: donor, health literacy, Internet, kidney, readability, transplant

Introduction

There are an estimated 286,942,362 people in USA who are regular Internet users, accounting for 88% of the total population [1]. According to the Pew Research Center, 72% of Internet users looked online for health information within the past year. Of these online health seekers, 77% of people started their search at a search engine such as Google, Bing or Yahoo [2]. With such a high proportion of patients utilizing online resources to guide
health care decision-making, it is important to analyze whether or not Internet materials are providing comprehensible material for patients.

Multiple readability formulas were developed in the 1940s as a way to analyze the difficulty of adult reading material. Pioneers within the field such as Rudolph Flesch and Edgar Dale devised formulas that helped quantify the reading difficulty of a particular document. Further progress was made in the 1970s with Peter Kincaid’s Flesch–Kincaid formula, which allowed the army to assess the difficulty of technical manuals [3].

The Institute of Education Sciences measured adult literacy in measuring prose, document and quantitative skills in over 19,000 subjects. In this study, only 15% of the sample scored at the highest level in all three categories (equivalent to a university undergraduate level), with the average reading level measured as between seventh and eighth grade [4]. As such, the National Institute of Health recommends patient education materials to be written at approximately a seventh grade level [5].

Previous studies in the pediatric literature have determined that online materials designed for adults in general pediatric patient education were written at inadequately advanced levels, which hindered parental comprehension about their children’s conditions. The authors concluded that clinical understanding between the physician and parent could be optimized with online reading material that was better tailored in accordance to the particular patient’s education and health literacy level [6].

Historically, there has been a socioeconomic divide between living donor recipients and deceased donor recipients. Living donor recipients as a group are more likely to be white, have a higher education level and to have private insurance. Patients with low socioeconomic status or of African American descent are less likely to receive a living donor kidney transplant [7]. Studies have shown that living donor recipients have statistically significant higher health literacy rates compared with deceased donor recipients [8]. Dageforde et al. administered a short literacy survey to 105 living donors, 103 living donor recipients and 152 deceased donor recipients. In all, 52% of living donor recipients achieved a score that qualified as having a ‘high health literacy’ compared with 40% of deceased donor recipients. Of the living donor recipients, 9% received a low health literacy rating as opposed to 14% of the deceased donor recipients. The level of educational attainment between living donor recipients and deceased donor recipients was similar with both groups having a mean of 13 years of education with a standard deviation of 3 years. After controlling for age, race, sex, education and race by education interaction effect, deceased donor recipients were more likely to have low or moderate health literacy compared with living donor recipients (P = 0.02) [8]. However, there has been no study to date comparing the readability of online living donor recipient materials versus the readability of deceased donor recipient materials.

**Materials and methods**

Using the largest Internet search engine, Google (Google Inc., Mountain View, CA, USA), two separate searches were conducted. Within the first search, the terms ‘Living Donor Kidney Transplant’ and ‘Recipient’ were queried into the search engine. The terms ‘Deceased Kidney Donor Transplant’ and ‘Recipient’ were queried into the search engine for the second search. All websites were accessed on 8 October 2016. Cookies, user information and location were all disabled prior to each search in order to eliminate bias in the search results. The top 10 results from each search were each separately pasted into a Microsoft Word Document in a plain text format (Microsoft Corp., Redmond, WA, USA) and edited in order to exclude imaging, links and diagrams. Exclusion criteria included sponsored links, non-English websites, pages with <30 sentences, non-functional websites, duplicates, scientific journal articles and websites containing irrelevant material to the original search.

Readability analysis was performed through the Readability Studio Professional Edition Software (Oleander Software, Ltd, Vandalia, OH, USA). The 10 most commonly used readability scales were used in this analysis, with each of them providing a unique set of variables in approximating USA reading grade level (Table 1). The Coleman–Liau Index utilizes the number of characters and sentences per 100 words in deriving its grade level formula. The Flesch–Kincaid Grade Level utilizes the total number of words, sentences and syllables within a given text to determine its readability. The result corresponds to an approximate US grade level. The Flesch Reading Ease also incorporates the total number of words, sentences and syllables within a given text to determine its readability. However, the scale is scored from 0 to 100 with 0–30 representing the reading level of a college graduate, the highest level of difficulty, and each subsequent increasing score representing a lower level of difficulty. The FORCAST scale calculates the readability of a document from the number of monosyllabic words. The Fry graph utilizes three randomly selected 100 word passages and analyzes the number of sentences and syllables in determining a document’s readability. The Gunning Fog Index utilizes average sentence length and the proportion of complex words (three or more syllables) to regular words in determining readability from a scale of 6–17, with 17 being the highest level of readability. The New Dale–Chall Readability formula utilizes sentence length and number of familiar words in calculating readability. Familiar words were 3000 common words that have been deemed to be comprehensible to most fourth-grade students. The New Fog Count test calculates readability through sentence length and the number of words containing three or more syllables. The Raygor Readability Estimate calculates readability through plotting the average number of sentences and letters per 100 words along with the number of 6+ characters per 100 words. The SMOG readability formula utilizes the number of sentences as well as the number of polysyllables (words with three or more syllables) to determine the readability of a certain passage.

**Results**

Overall, the mean reading level for the living donor materials was 12.54 (range 9.2–17) (Figure 1). For the deceased donor materials, the mean reading level was 12.87 (range 8.7–17) (Figure 2). A two-sample t-test showed no statistical difference between the readability levels (P = 0.73). Of the 20 websites that were analyzed, 14 (70%) were affiliated with academic medical centers. All living donor recipient sites results were academic university-based sites. Out of the 10 websites for deceased donor recipients, 4 were affiliated with academic medical centers, 4 were third-party websites and 2 were government affiliated websites. One site from the living donor recipient search was excluded, as it was a duplicate site. Five sites from the deceased donor recipient search met exclusion criteria as published material in scientific journals.
For living donors, the overall Coleman–Liau readability score was 12.7 (range 10.8–16), Flesch–Kincaid was 11.5 (range 9.2–14.6), Flesch Reading Ease was 44 (range 24–60) (Supplementary data, Figure S3A), FORCAST was 11.9 (range 10.9–12.8), Fry was 15 (range 11–17) (Supplementary data, Figure S4A), Gunning Fog was 11.8 (range 9.4–14.1), New Dale–Chall was 11.6 (range 9.5–14), Raygor Estimate was 14 (range 10–17) (Supplementary data, Figure S5A) and SMOG was 12.7 (range 10.8–15.2).

For deceased donors, the overall Coleman–Liau readability score was 12.5 (range 10.4–14.6), Flesch–Kincaid was 12.6 (range 8.7–17.6), Flesch Reading Ease was 45 (range 31–58) (Supplementary data, Figure S3B), FORCAST was 11.6 (range 10.9–12.3), Fry was 14 (range 10–17) (Supplementary data, Figure S4B), Gunning Fog was 12.4 (range 9.9–15.2), New Dale–Chall was 12.3 (range 9.5–14), Raygor Estimate was 14 (range 10–17) (Supplementary data, Figure S5B) and SMOG was 13.3 (range 10.8–15.2).

Table 1. Readability formulas

| Scale                  | Variables                                                                 | Formulas                                                                 |
|------------------------|---------------------------------------------------------------------------|---------------------------------------------------------------------------|
| Coleman–Liau Index     | Average number of letters per 100 words (L) and average number of sentences per 100 words (S) | \[ G = \frac{(5.88 \times C)}{W} - \frac{(29.5 \times S)}{W} - 15.8 \] |
| Flesch–Kincaid Grade Level | Average number of syllables per word (SY) and average number of words per sentence (W) | \[ G = \frac{(11.8 \times B)}{W} + \frac{(0.39 \times W)}{S} - 15.59 \] |
| Flesch Reading Ease   | Average number of syllables (B), average number of words per sentence (W), average number of sentences (S) | \[ I = \text{ROUND} \left( 100 \times \frac{206.835}{W} - \frac{84.6}{S} - 1.015 \right) \] |
| FORCAST               | Number of single-syllable words in a 150-word sample (SS)                | \[ G = 20 - (M/10) \] |
| Fry Graph             | Average number of sentences and syllables per 100 words                  | • Extract a 100-word passage from the selection                             |
|                       |                                                                          | • Count the number of sentences in each passage                             |
|                       |                                                                          | • Count the number of syllables in each passage                              |
|                       |                                                                          | • Find the point on the chart                                                |
| Gunning Fog Test      | Number of sentences (S), number of words (W), number of words with three or more syllables (C) | \[ G = 0.4 \times \frac{W}{S} + \frac{(C)}{W} \times 100 \] |
| New Dale–Chall       | Average number of words per sentence (AW) and percent unfamiliar words (%U) | \[ (0.1579 \times %U) = (0.0496 \times AW) \] |
| New Fog Count        | Number of complex words (C), number of easy words (E), number of sentences (S) | \[ G = \frac{[E + (3 \times C)]}{S} - 3 \] |
| Raygor Readability Estimate | Average number of sentences and long (six or more characters) words per 100 words | • Extract a 100-word passage from the selection                             |
|                       |                                                                          | • Count the number of sentences                                              |
|                       |                                                                          | • Count the number of words that are six or more letters                    |
|                       |                                                                          | • Find the point on the chart                                                |
| SMOG                  | Average number of words with three or more syllables (C) and average number of sentences (S) | \[ G = 1.0430 \times C + 3.1291 \] |

Fig. 1. Readability levels measured by eight scales for living donor materials.
10.8–16.3). Using the Flesch–Kincaid scale, the mean readability scores of university-based, government and third-party sites were compared. The mean readability score of university-based sites was 12.45, compared with 10.45 with government sites and 11.35 with third party sites. These means were not statistically significant different as determined by one-way analysis of variance (ANOVA) \(F(2,7) = 1.76, P = 0.24\).

## Discussion

The findings of our study revealed an overall readability of 12.54 for living donor recipient materials found online. The overall readability for deceased donor recipient online materials was 12.87, with no statistical difference between the two cohorts \((P = 0.73)\). Both living donor recipient and deceased donor recipient materials were written at an average difficulty that corresponded to a university readability level. Out of the 20 articles analyzed for readability, none of the articles met the seventh-grade level that the National Institute of Health recommends for patient education material. The majority of these articles were from academic medical centers, which may have further contributed to the high readability of the materials. When comparing university-based, government and third-party sites in the deceased donor recipient group, there was not a statistically significant difference in the readability levels between categories.

Overall, the readability of online materials for both living donor recipients and deceased donor recipients remain far too high for the corresponding health literacy rates among patients with chronic kidney disease requiring transplantation. There was a discrepancy noted in the distribution of site types between living and deceased donor material queries. All 10 search results from the living donor search query were affiliated with academic medical centers. Out of the 10 websites for deceased donor recipients, only 4 were affiliated with academic medical centers. Despite the higher concentration of academic-affiliated sites among living donor sites, there was no significant difference in readability between the two groups (12.54 among living donor material versus 12.87 among deceased donor material). This may be contrary to the popular belief that academic center sites may have a higher readability than third-party or government sites. Future studies should be considered in evaluating the readability between academic and nonacademic sites.

As discussed previously, deceased donor recipients are more likely to be of a lower socioeconomic status, of a minority group and are more likely to have an overall lower health literacy rate compared with patients who receive living donor recipients \([7]\). Given the high readability level of the patient education material, those with lower health literacy may not receive adequate education regarding the benefits and risks associated with living donor kidney transplants. The mismatch between patient literacy and the material readability may lead patients to search for other mediums such as forums or popular non-scientific pages that are more appropriate in readability, but less medically accurate. This discrepancy may have an impact on a patient’s decision in ultimately not pursuing live donor kidney transplantation.

There were several limitations to our study. While we utilized 10 different scales, the readability scales commonly used word, syllable and sentence length in order to calculate readability. With the exception of the New Dale–Chall scale, which incorporated a list of 3000 words deemed to be familiar to most fourth graders, the other scales failed to incorporate word familiarity along with word length in determining readability. Thus familiar words such as ‘transplantation’ that had long word lengths but wide familiarity may have artificially increased the readability of a particular document. In addition, website format was not taken into consideration in our study. For example, a website that exclusively used paragraph form in its content description may have been less readable than a website that incorporated a frequently asked questions format supplemented with graphs and figures. Future studies or alternative readability scales catered specifically to scientific writing should be explored.

According to the National Kidney Foundation in 2014, 17,107 kidney transplants took place in USA. Of these, 11,570 were deceased donor transplants, while 5,537 were living donor transplants \([9]\). It has been well-established that living-donor allografts are superior to deceased-donor allografts. For living-donor
recipients, the 5-year post-transplantation rate has been quoted at 91%. For deceased, non-extended-criteria donor recipients, the 5-year survival rate is 84%. For patients that receive a deceased, extended-criteria donor transplantation, the 5-year survival rate is 70% [10, 11]. As of January 2016, 100,791 people in the USA were awaiting a kidney transplant. The median wait time for a transplant is 3.6 years, but is highly dependent on region and blood type. In 2014, 4,761 died while on the kidney transplant list, while another 3,668 people became too sick to receive a transplant [9].

Dageforde et al. proposed a multifactorial model of living donor recruitment. Key components such as cognitive function, health literacy, age, race and education played a role in successfully improving one’s chances of obtaining a living donor. One of the crucial aspects from the recipient’s perspective is the ability to communicate effectively to a potential donor the risks, benefits and basic principles of live donor transplantation [8]. The current readability of available online material for deceased donor recipients may not match the overall health literacy rate of this group. Thus, the unmatched readability may hinder full patient comprehension of the benefits of a potential living donor recipient within the group of patients who are on the waiting list for a deceased donor. If patients are provided appropriate reading materials that are simple, concise and match corresponding health literacy rates, perhaps there would be an increase in patients who actively seek a live donor. The transplant team is a nuclear entity composed of a multitude of professionals ranging across different fields such as physicians, social workers and transplant coordinators. Through a united effort, different individuals on the transplant team can individualize patient education and understanding of the transplant process to an appropriate level that matches the patient’s health literacy. This individualized approach will help bridge the gap that exists in the readability of the online materials available for potential kidney recipients. With the development of multiple readability scales, transplant centers should pre-screen the readability of online patient information prior to publication in order to tailor the material to an appropriate level. Modifications of current online literature and altering readability levels could have profound effects on overall patient comprehension of differences in outcomes between deceased and live donor organs, thus increasing the current living to deceased donor ratio.

**Supplementary data**

Supplementary data are available online at http://ckj.oxfordjournals.org.

**Conflict of interest statement**

None declared.

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