Readability of Written Materials for Chronic Kidney Disease Patients:

A Systematic Review

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Abstract

Background

The average patient has a literacy level of US grade 8 (age 13-14), but this may be lower for people with Chronic Kidney Disease (CKD). Current guidelines suggest patient education materials should be pitched at a literacy level of around 5th grade (age 10-11). This study aims to evaluate the readability of written materials targeted at CKD patients.

Study Design

Systematic review.

Setting & Population

Patient information materials aimed at adults with CKD and written in English.

Search Strategy & Sources

Patient education materials designed to be printed and read, sourced from practices in Australia and online at all known websites run by relevant international CKD organisations during March 2014.

Analytical Approach

Quantitative analysis of readability using Lexile Analyser and Flesch-Kincaid tools.

Results

We analysed 80 materials. Both Lexile Analyser and Flesch-Kincaid analyses suggested the majority of materials required a minimum of grade 9 (age 14 – 15) schooling to read them. Only 5% of materials were pitched at the recommended level (grade 5).

Limitations

Readability formulas have inherent limitations and do not account for visual information. We did not consider other media through which CKD patients may access information. Although the

study covered materials from the USA, UK and Australia, all non-internet materials were sourced locally, and it is possible some international paper based materials were missed. Generalizability may be limited due to exclusion of non-English materials.

Conclusions

These findings suggest that patient information materials aimed at CKD patients are pitched above the average patient's literacy level. This issue is compounded by cognitive decline in CKD patients, who may have lower literacy than the "average" patient. It suggests that information providers need to more carefully consider their audience when preparing patient information materials, including user-testing with a low-literacy patient population.

Introduction

Written patient information resources reinforce verbal communication between doctors and patients [1,2]. Printed resources can be introduced during clinical encounters and provide a concrete record which patients can refer back to, check understanding, and use as a foundation for asking further questions and learning to self-manage their care[3]. Previous studies suggest that existing patient education materials may be inadequate for CKD patients' needs[4 5]. This is important, as good self-care can improve quality of life and delay progression of kidney disease. A recent study examining the suitability of US-produced CKD patient information materials found most materials were adequate but few were outstanding[6]. We don't have reason to believe this issue is confined to the USA. To date, no study has systematically examined the readability of written materials aimed at CKD patients.

Estimates of Chronic Kidney Disease (CKD) stage 1-4 prevalence range from 0.6-42.6% depending on stage and location; a recent systematic review found the higher quality studies produced estimates closer to between 1.7 and 8.1% of the adult population, which is similar to diabetes mellitus prevalence [7]. In the US, CKD prevalence in adults aged over 20 is estimated at around 15% according to the most recent (2007-2012) National Health and Nutrition Examination Survey[8] (NHANES). The age-adjusted prevalence estimate based on 1999-2004 NHANES data is just over 13%[9]. In England, estimates of doctor-diagnosed CKD are below 2.5%[10]; however age-standardised population estimates of stage 3-5 CKD in the UK are up to 10.6% [11]. In Australia, rates of CKD were similar for both men and women, at around 10%[12].

In Australia, up to 60% of adults lack the skills needed to understand and use information related to health e.g. locate information on a bottle of medicine [13]. People with low health literacy have a

limited capacity to navigate the healthcare system and they have difficulties obtaining, processing, understanding, and engaging with health information to make informed health decisions[14]. Limited health literacy impairs patients' ability to self-manage their care, participate in shared decision making, adhere to treatment and medication plans, and monitor lifestyle factors such as diet[15]. Estimates of low health literacy among kidney disease patients from a small number of studies (mostly of dialysis patients) range from 5% to 50% [16] (in a single CKD cohort 19% of patients had low health literacy); a recent systematic review (in which all studies were from the USA) suggested a number closer to 23% (95% confidence interval 20.6-24.87%)[17].

Reading ability is important for health literacy, since health literacy involves locating and evaluating information. Many health literacy measures (e.g. REALM[18]) focus entirely on verbal knowledge or other aspect of reading ability as a proxy for health literacy, whereas others (e.g. Newest Vital Sign[19]) include elements of numeracy. As such, estimates of health literacy may be affected by the measures used. Previous work in the field of arthritis and among low literacy populations in Australia concluded that patient education materials are frequently pitched well above the literacy level of the "average" patient [1,2,20-22]. In the US, the "average" adult patient's reading level roughly equates to that of a student in U.S. grade 8 (age 13-14). Persons with limited health literacy skills are closer to U.S. grade 5 (age 10-11). Approximately 20% of patients read at 5th grade or below, rising to 40% in over 65 populations[23]. Thus, many patients do not reap the benefits of patient information resources as they lack the skills required to read, understand, and engage with them [24]. Written resources can support patients when they provide necessary information at an appropriate level for the lay reader[1] and are supported by the patient-

carer relationship[25]. Clear, comprehensive and user-friendly patient information materials should facilitate optimal patient understanding and improved health outcomes.

For patients with limited health literacy, the reading level of patient materials will affect comprehension. The fastest and simplest way to evaluate the difficulty of a text is to quantify text complexity with a computerised readability formula that measures specific features of text. The Lexile Framework is reported to be a reliable and valid measure of readability, with a relatively solid theoretical framework and good psychometric properties[26,27] that has previously been used to evaluate medication leaflets[28] and is one of the formulas suggested by the Centers for Disease Control for calculating readability[29]. The Flesch-Kincaid Grade Level formula has been validated in the health care setting using McCall-Crabbs Reading Passages, the Dale-Chall criterion, and the Cloze procedure, and is easily accessible in Microsoft Word [30]. Between them, these two formulae examine three different elements of text - word length, sentence length, and word frequency - to produce readability estimates.

We aimed to investigate the current state of English-language printed information materials targeted at CKD patients, using two quantitative readability formulas.

Methods

Search strategy

After advice from information specialists, experts, clinicians, and patients, we conducted an extensive search for CKD patient information materials in March 2014. This search involved obtaining patient education materials distributed at Australian hospitals, and those distributed by Australian nephrologists in their clinical practice. Materials were also obtained from experts in the field, including CKD educators, and PhD scholars conducting research involving CKD patient information needs.

Materials were also sourced online by searching all known English-language websites run by relevant CKD organisations both in Australia and overseas. These websites included: non-profit organisations (e.g., Kidney Health Australia, US National Kidney Foundation, etc.); pharmaceutical companies (e.g., Amgen); academic organisations (e.g., the Australia and New Zealand Society of Nephrology, the Renal Association); health facilities (e.g., UK University Hospitals; Edren); and government departments (e.g., Centers for Disease Control & Prevention). The relatively small number of materials aimed specifically at mild-moderate CKD identified in these searches suggested little added benefit in an exhaustive search of primary care providers – despite the fact that early CKD is mostly managed in primary care.

Selection criteria

Included materials were free English-language patient information materials designed to be printed and read; aimed at adults with CKD stages II-IV; and describing management, treatment or complications of CKD.

Materials were excluded if they were not designed specifically to be read in hard copy, or if the information was available only on websites and not for download as pdf, because our focus was on materials that would be distributed during a practitioner consultation. We excluded materials presented predominantly as infographics, or in visual format, or other non-text format; because cultural factors can influence their interpretation[31]. Also excluded were materials aimed at children, adolescents, parents, or carers of people with CKD. We included only information about CKD II-IV, so excluded information about dialysis choices or transplantation, and information that was predominantly patient or carer testimony.

Assessment tools

We used 2 readability tools to evaluate the written information about CKD; the Lexile analyser and the Flesch-Kincaid Grade Level formula.

The Lexile Analyzer evaluates two features of prose text: word frequency (within the Lexile Analyser corpus of approximately 600-million US-English words) and sentence length. These are proxies for syntactic complexity and semantic demand respectively. Greater weight is given to sentence length according to the formula below, with the resulting Lexile score expressed as L[32].

Theoretical logit = (9.82247*LMSL)-(2.14634*MLWF)-constant

where LMSL = log of the mean sentence length and MLWF = mean of the log word frequencies.

Lexile calibration = (logit + 3.3)*180 + 200

Lexile scores can be loosely interpreted in terms of U.S. grade levels. Possible scores range from 200L to 1700L; higher scores indicate greater text complexity. Scores can apply to readers or texts – with the aim of matching readers to texts. A reader with a Lexile reading measure of 900L is expected to comprehend approximately 75% of a text measured at 900L [33]. In this analysis we focus only on Lexile text measures. Interquartile ranges for Lexile text scores at different grade levels are presented in Table 2.

The Flesch-Kincaid Grade Level formula estimates the U.S. grade level required to read text using the average number of words per sentence and the average number of syllables per word and is expressed as a grade. For example, text that is scored between 8.0 and 8.9 should be readable by an "average" student in grade 8. We used Microsoft Word to calculate it by enabling "readability statistics". The formula is:

$$0.39\left(\frac{total\ words}{total\ sentences}\right) + 11.8\left(\frac{total\ syllables}{total\ words}\right) - 15.59$$

Assessment dataset

Each patient information document was prepared for analysis as per Lexile Analyser guidelines, by converting (or removing) any non-prose elements into prose, ensuring correct punctuation, and changing spelling from Australian or British English to US English where necessary. The Lexile Analyzer analyses "chunks" of approximately 125 words (retaining complete sentences), and aggregates the measures of these chunks to arrive at an overall score. This is in recognition of the fact that different sections of text may have different features (e.g. longer sentences, more

high-frequency words). Four 125 words sections are regarded as the minimum to ensure an accurate and reliable result[34], thus we set an inclusion criteria of minimum 500 words.

The same prepared text was used for both Lexile analysis and Flesch-Kincaid Grade Level score; the first using the Lexile Analyser website, and the latter using the readability statistics feature in Microsoft Word.

All materials greater than 500 words in length were assessed using the Lexile Analyzer and the Flesch-Kincaid Grade Level tools. Readability data collected for each document includes: a Lexile score, mean sentence length, log word frequency, and the Flesch-Kincaid grade level score. Descriptive statistics and Pearson correlation between the Lexile Score and Flesh-Kincaid Grade Level were calculated. Materials less than 500 words were analysed separately.

Results

After removing duplicate materials found in more than one location, 494 materials were screened against criteria, and after screening, 94 remained (see Figure 1). These 94 consisted of information and advice on topics such as CKD disease (e.g. what it is and who is at risk); related diseases (e.g. diabetic kidney disease, renal bone disease); and lifestyle and self-management (e.g. diet, exercise, sexuality). Excluded materials included those that focused on dialysis, transplant or donation, materials that were primarily visual, that were not aimed at CKD patients, and that were advertising (rather than information) materials. See Figure 1 and Table 1. Of the 94 materials, 80 contributed to the quantitative analysis; 14 were excluded because they were shorter than the 500 words required by the readability tools. All excluded materials were less

than 5 standard (US Letter or A4) pages in length. For reference, the descriptive statistics for the 14 excluded materials are presented in Table 2.

The average text Lexile score obtained for the 80 materials > 500 words was 1120.9. This translates to equivalent complexity read by students in U.S. grades 9 to 12 (aged 14 – 18). Similarly, the Flesch-Kincaid Grade Level analysis indicated that the average grade of schooling required to read these CKD patient materials was approximately U.S. grade 9 (aged 14 – 15). Correlation between the two measures was 0.89 (Figure 2).

Table 2 describes the distribution of scores for the 80 materials across the two readability measures, and histograms are presented in Figure 3. Mapping the Lexile scores directly to grade levels is challenging, as there is considerable overlap between Lexile text ranges, reflecting the variation of student abilities within a grade level. For this reason, we also show two published alternative interquartile reference ranges (IQR) for the Lexile scores, based on normative grade level data and designed with different purposes. The 2009 Text Demand Study examined textbooks specifically designed for grade levels[33]; the 2012 Common Core State Standards study identified the level students should be reading at to be college or career-ready by the end of grade 12[33,35]. Our interpretation of Lexile scores is based on the 2009 data, because this is more relevant for the CKD patient population. The interquartile range of text Lexile scores for grade 8-level readers is 900L to 1010L (for grade 5 it is 730L to 850L)[33]. **Error! Reference source not found.**Only 18 of the 80 materials (22.5%) examined using the Lexile analyser are pitched at a level that would be readable for the "average" (grade 8 reading level) patient (≤1010L), and none are suitable for patients with limited (grade 5) literacy typical of a CKD patient. Based on the Flesch-Kincaid measure, 35 materials (43.8%) are pitched at a grade level suitable for use in the

"average" patient population. However, only 5% (4) are suitable for the CKD patient population with limited health literacy based on readability recommendations[23] (Figure 2).

The five materials within (or just outside – see Figure 2) the Flesch-Kincaid grade 5 level were booklets and factsheets on different topics related to CKD, produced from 2010-2012. Two were produced by the same US government organisation, two by a non-profit organisation, and one by a pharmaceutical company (supported by non-profit organisations and health facilities). There did not appear to be any discernable pattern to the documents characterised as more "readable" – the same organisation that produced the "most readable" documents also produced several that are suitable only for grade 10 and above.

Discussion

We found the majority of written resources available for patients with CKD demand literacy levels beyond that of the "average" patient, and well above that of low literacy CKD patients. Whilst clinician-patient communication is a critical part of any treatment plan, written patient information materials are an important vehicle for disseminating information to patients that they can review outside of the clinical encounter [25]. Previous investigations into the comprehensibility of patient materials designed for arthritis patients indicated that the vast majority of these were too complex to be usable for the average patient[36]. Our hypothesis that materials targeted at CKD patients may also be too complex for the average patient is supported by this work.

The implications of this for written information providers are quite clear – for patient information materials to benefit their target audience, they must be written at a level accessible to the target patient population. Given that 40-80% of medical information given by healthcare

providers during consultations is forgotten [37], it follows that if CKD patients cannot read and understand the written information provided, their ability to engage with their own health care and treatment may be limited[25]. Well-informed patients engaging in appropriate self-care and supported should achieve improved health outcomes and reduced risk of disease complication[5].

It is worth noting here that a disproportionate number of materials identified in our search were aimed at end stage renal disease patients, with relatively few focused on CKD stages 1-4. This is important, because the majority of CKD patients never progress to end stage kidney failure: either the progression of their kidney disease is slow, or comorbid conditions such as cardiovascular disease and cancer tend to claim their lives first. These patients may have the most to gain from information on how to live well with kidney disease yet there is relatively little information targeted directly at them. When information about self-management and lifestyle change is "hidden" in booklets focusing on dialysis or transplantation, it becomes less accessible to patients who have not (yet) progressed to end stage renal disease. This suggests that the CKD patient population is generally underserved in terms of written patient information. Progress towards this end includes development of the Chronic Kidney Disease Self-Management Knowledge Tool (CKD-SMKT), which is designed for CKD patients with low health literacy, and can help clinicians to understand their knowledge deficits[38].

There are many different readability formulas that quantifiably describe specific, objectively measured features of text, with varying degrees of agreement. The great advantage of readability formulas such as the Lexile Analyser and Flesch-Kincaid is that they provide a fast, computerised assessment of the reading level of a text. The latter is included as standard in one of the most widely used word processing programs (Microsoft Word), so can be easily accessed by document developers as a first automated check for the complexity of language used. The

findings from this study indicate that even a basic assessment of readability is probably not completed when designing patient information materials. This suggests a lack of understanding among information providers about both average literacy levels, and the needs of patients with low literacy.

A limitation of this study lies with the operational definition of "readability", because text alone accounts for only a few of the elements that determine document comprehension. Furthermore, the word frequency measure of the Lexile analyser may result in some overestimation of semantic difficulty if CKD patients are more familiar with certain medical terms than they appear in the general lexicon. We did not attempt to adjust for this since we did not want to make assumptions about patients' knowledge of medical language. A more thorough analysis might conduct user-testing with CKD patients in order to produce a more accurate estimate of familiarity of medical terms, and this could inform development of future materials.

All readability formulas are limited in terms of what they can tell us about how patients actually engage with the text. Features of text such as layout, use of headings, tables, lists, summaries, repetition, visuals, tone, and style, all contribute to the usability of a document and how easily information can be accessed. The documents analysed for this paper were first converted to prose, as this is a requirement of the Lexile Analyser. Thus titles, headings, and short captions were all removed prior to analysis, even though these features alone can contribute to a document's readability. The Lexile Analyser does have a correction (subtract 120L) for materials that have visual elements or "scaffolding" supporting the text[34]; however we did not apply this because we have not seen it validated in texts of this nature. We accept that reading level of the documents we analysed may be overestimated as a result; however, this does not

change our overall conclusion that much work remains to be done in developing appropriate materials for CKD patient education.

Formulas do not account for vagueness or inconsistency in the text, typographical cues, or the impact of grammar and punctuation on readability [39]. Neither do they evaluate factors relevant to numeracy, which is an element of health literacy that is highly relevant for CKD patients who need to understand and monitor test results, medications, and diet[16]. For document developers, many of these features can be evaluated using the Simply Put checklist[29]; for document reviewers, the Suitability Assessment of Materials [23] and Patient Assessment Materials Assessment Tool (PEMAT)[40] offer a systematic method for identifying features of a text that may enhance or interfere with comprehension. Examination of CKD patient materials using these tools is a focus of our future work.

The extent to which this study is generalizable is difficult to assess. While we attempted to be systematic in gathering materials for this study, it is likely we had better access to local resources than international ones, and the experts we consulted were contacts of the authors based in Sydney, Australia. On the other hand, of all the printed materials we analysed, only one was not also available online. There is no standard strategy for searching for internet based materials and the web is dynamic, with information changing constantly. It remains possible therefore we may have missed some documents, or that documents previously not available have become available since our search was conducted. The information gathered was also only in English and from Australia, the USA and UK. We identified some very good online resources but did not include them because they were not designed to be printed and read – they were designed to be used interactively. Thus we have by design excluded materials that may be designed for patients to seek out on their own. Web content is typically written and presented quite differently to printed

content, and it is possible that CKD-targeted web content is pitched at a lower reading level than the printed materials we found (although this was not the case in 2004[41]).

Finally, written materials are but one avenue via which patients obtain information about their disease and self-care options, and low-literacy patients may indeed seek information from other sources such as through more literate relatives or friends, or audio-visual materials. Nevertheless, organisations dedicated to supporting CKD patients in 3 countries all produced materials that may be too difficult for their intended audience. When the needs of low-literacy populations are not adequately addressed, health inequalities may increase as those within a low-literacy population lack the ability, knowledge and resources to engage in effective self-management and slow disease progression (where this is possible).

In summary, the main finding from these analyses is that many CKD patient information materials are currently written at a level well above the literacy level of an average patient, suggesting that information providers must pay more attention to patient information needs, to ensure that patients understand the information provided well enough to know what to do. It is difficult to justify the time, effort, and expense of producing patient information materials if the intended audience is unable to effectively access and use the information. User testing of patient materials together with more thoughtful document design may help overcome this problem.

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Table 1: Characteristics of Included Materials

Characteristics of Materials	**Number of Materials n (%) (Total N=94)**	**Type of publication (n)**		*Excluded * (n, total=14)*
Topic of Information		More than 5 pages	Less than 5 pages	
CKD Specific	24 (25.5)	12	12	*5*
Related Conditions	35 (37.2)			
Anaemia	7 (7.4)	5	2	*1*
Glomerulonephritis / IgA Nephropathy	6 (6.4)	0	6	*0*
Diabetes	5 (5.3)	2	3	*0*
Hypertension	4 (4.3)	3	1	*0*
Bone Disease	3 (3.2)	0	3	*1*
Cardiovascular Disease	3 (3.2)	1	2	*0*
Cystic Kidney Disease	3 (3.2)	2	1	*0*
Alport Syndrome	2 (2.1)	0	2	*0*
Other	2 (2.1)	1	1	*0*
Lifestyle	34 (36.2)			
Diet and Nutrition	17 (18.1)	7	10	*5*
Self-Management	10 (10.6)	6	4	*2*
Sexuality	4 (4.3)	3	1	*0*
Exercise	3 (3.2)	2	1	*0*
Other	1 (1.1)	1	0	*0*

Produced By:	*UK*	*USA*	*Europe*	*Australasia*
Non-Profit Organisation	5 (5.3)	26 (29.7)	0	26 (27.7)

Pharmaceutical Company	0	4 (4.3)	0	1 (1.1)
Government	0	8 (8.5)	0	1 (1.1)
Health Facilities	5 (5.3)	1 (1.1)	0	16 (17.0)
Academic Source	0	1 (1.1)	0	0
Funded By:	UK	USA	Europe	Australasia
Non-Profit Organisation	5 (5.3)	20 (21.2)	0	22 (23.4)
Pharmaceutical Company	0	21 (22.3)	1 (1.1)	1 (1.1)
Government	5 (5.3)	8 (8.5)	0	5 (5.3)
Health Facilities	0	1 (1.1)	0	4 (4.3)
Media/Advertising	0	0	0	1 (1.1)
Endorsed By:				
Non-Profit Organisation (NPO)		14 (14.9)		
Pharmaceutical		11 (11.7)		
Health Facilities		13 (13.8)		
Government		19 (20.2)		
Academic		13 (13.8)		
Other		8 (8.51)		
Not Stated		35 (37.2)		
Note: some materials have multiple endorsements so totals do not add to 100%				
Year of Publication:				
2010 – 2013		55 (58.5)		
2005 – 2009		17 (18.1)		
2000 – 2004		7 (7.4)		

Not Stated	15	16.0)

* 14 materials were excluded from the main analysis because their text length was shorter than required by the readability tools. All excluded materials were less than 5 pages, often much shorter.

Table 2: Descriptive statistics for all (n=94) materials and distribution of scores for final (n=80) Lexile and Flesch-Kincaid Analyses

	n	Mean	Standard Deviation	Minimum	Maximum	Median	Target	
							5th grade	8th grade
Lexile Score	80	1120.9	119.7	870	1370	1125	<850	<1010
	14	941.4	118.1	670	1180	943.3		
Flesch-Kincaid Grade Level	80	9.0	1.9	5.2	13.7	9.2	<5.9	<8.9
	14	6.4	1.4	4.4	9.8	6.2		

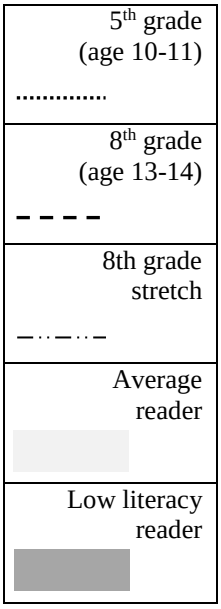
Grade Level (n=80)	Study materials within Flesch-Kincaid Grade Level N (%)	Range of Lexile Scores	Study materials within Lexile range N (%)	Lexile IQR for grade Text Demand Study 2009*	*Lexile IQR for grade CCSS Text Measures 2012†*
5	4 (5)	700-800		730-850	*830-1010*
6	8 (10)	800-900	2 (3)	860-920	*925-1070*
7	12 (15)	901–1000	15 (19)	880-960	*970-1120*
8	11 (14)			900-1010	*1010-1185*
9	21 (26)	1001–1100	16 (20)	960-1100	*1050-1260*
10	14 (18)			920-1120	*1080-1335*
11	3 (4)	1101–1200	29 (36)	1070-1220	
12	4 (5)	1201–1300	12 (15)		*1185-1385*
13	3 (4)	1301–1400	6 (8)		

* Interquartile (IQR) reference range from research conducted by MetaMetrics examining collections of textbooks designated for specific grades[33] (corresponding to grade level on left).

† Interquartile (IQR) reference range from Common Core State Standards (CCSS) (corresponding to grade level on left). These reflect the level students should be reading at in order to be college and career-ready by grade 12[33,42]. They are referred to as "stretch" measures.

Figure 1: Flow chart of materials selection

Figure 2: Correlation between Lexile and Flesch-Kincaid results



Dotted horizontal lines indicate the 75th percentile of 5th grade (850L) and 8th grade (1010L) Lexile text scores. Upper horizontal line is the 75th percentile of "stretch" (CCSS) 8th grade text scores.

Vertical lines indicate upper limit of Flesch-Kincaid scores for grade 5 (5.9) and grade 8 (8.9)

Light shaded area represents patient materials that could be read by the "average" patient.

Dark shaded area represents materials that could be read by a low literacy patient.

Figure 3: Distribution of readability scores