

Assessment of Printed Patient-Educational Materials for Chronic Kidney Disease

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Key Words

Chronic kidney disease · Health literacy · Patient education materials

Abstract

Background: Awareness of chronic kidney disease (CKD) is suboptimal among patients with CKD, perhaps due to poor readability of patient education materials (PEMs). We reviewed the suitability and readability of common PEMs that focused on 5 content areas: basics of CKD, risk factors for CKD development, risk factors for CKD progression, complications of CKD and self-management strategies to improve kidney health. **Methods:** Three reviewers (nephrologist, primary care physician, patient) used the Suitability Assessment of Materials to rate PEMs on message content/stimulation of learning, typography, visuals and layout and determined literacy level. Mean ratings were calculated for each PEM by content area and overall (superior = 70–100; adequate = 40–69; inadequate = <40). Linear regression was used to determine the impact of literacy level on mean rating. **Results:** We reviewed 69 PEMs from 19 organizations, divided into 113 content area sections. Most (79%) PEM sections were ‘adequate’ (mean rating, 58.3%). Inclusion of patient-centered content and opportunities for patient interaction were associated with ‘superior’ ratings. Mean ratings

(SD) were similar across content areas: basics of CKD, 58.9% (9.1); risk factors for CKD development, 57.0% (12.3); risk factors for CKD progression, 58.5% (12.0); CKD complications, 62.3% (15.7), and self-management strategies, 62.2% (12.3). ≤6th grade literacy level (vs. >6th grade) was associated with an 11.7 point higher mean rating. **Conclusion:** Most PEMs for kidney disease were adequate. Outstanding PEMs shared characteristics of patient centeredness, a low literacy level, and patient interaction. Providers should be aware of strengths and limitations of PEMs when educating their patients about CKD.

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Introduction

Chronic kidney disease (CKD) affects millions of people in the United States [1] and is associated with cardiovascular morbidity and increased mortality at all stages [2]. Strategies to reduce CKD-related complications, including progression to end-stage renal disease (ESRD), and death, such as glycemic control in persons with diabetes, blood pressure control, reduction of proteinuria, avoidance of nephrotoxic substances (such as non-steroidal anti-inflammatory drugs) and diet and lifestyle modifications, are well-known to clinicians [3–5]. Implemen-

tation of these CKD risk modification behaviors requires not only clinician awareness, but also patient understanding and engagement in their health [6].

Published data suggest that <10% of individuals with CKD are aware of their kidney disease, including only 16% of individuals with complicated CKD [7, 8]. Beyond general awareness, perceived and objective knowledge of kidney disease are suboptimal among individuals actively receiving nephrology care [9]. National efforts are thus underway to increase patient awareness of kidney disease, including the development of patient educational materials (PEMs) for individuals with CKD and those at high risk of developing CKD [10].

With many printed PEMs now available, it is not clear which ones best provide patients with and at high risk of CKD with adequate health information and empower them to become better custodians of their CKD care. This is a particular concern for individuals with low health literacy, who represent over 35% of the adult United States population [11] and at least 18% of the adult CKD population [12]. Previous studies have demonstrated that web-based educational materials for CKD are difficult to understand [13]. As printed materials remain the cornerstone of office-based clinician-initiated educational efforts, understanding which materials maximize patient engagement in healthy behaviors is key to helping clinicians and patients achieve control of CKD risk factors, thereby minimizing CKD progression. The aim of this study was to evaluate the suitability (ease of understanding) and readability (reading level) of common printed PEMs for individuals with and at high risk of CKD, focusing on 5 content areas pertinent to such individuals: basics of CKD, risk factors for CKD development, risk factors for CKD progression, early complications of CKD and self-management strategies to improve kidney health. Results could help clinicians select the PEMs best suited for their patients, leading to more effective CKD education, potentially enhancing patient engagement and overall health.

Methods

Identification of CKD Patient Education Materials

We identified a large convenience sample of common PEMs using Internet search engines (Google and Yahoo) with the following search terms: 'Chronic kidney disease [CKD] patient education materials', 'CKD patient materials', 'CKD patient education resources', 'CKD patient resources', 'CKD patient education information', 'CKD patient information', 'CKD education materials', 'CKD education resources', 'CKD education information', 'CKD materials', 'CKD resources', and 'CKD information'. Web links that contained 2 or more of the above search terms were identified

and searched for PEMs. Non-English materials, materials that were purely web based (could not be downloaded and printed as a pdf, text or word document) or those that contained information solely for patients with ESRD were excluded.

We divided each printed material as appropriate into the following content areas: basics of CKD, risk factors for CKD development, risk factors for CKD progression, early complications of CKD and self-management strategies to improve kidney health. This process enabled us to evaluate whether a discrete section of a PEM would be useful in a particular clinical setting, for example, when discussing diet and exercise (self-management) versus anemia (complication of CKD).

Evaluation

Suitability of Assessment

We assessed PEM sections with an adapted Suitability Assessment of Materials (SAM) instrument [14]. This instrument was originally developed to evaluate the appropriateness and presentation of printed PEMs and has been adapted and validated for evaluation of health-related PEMs for many diseases including congestive heart failure [15], hypertension [16], and stroke [17]. The adapted SAM used in these analyses consisted of 26 items grouped into 4 different domains: message content (including learning stimulation and cultural suitability), text appearance/typography, visuals/graphics, and layout/design.

Three reviewers (D.S.T., nephrologist; E.D., general internist; J.R., a 54-year-old Caucasian patient followed in primary care with proteinuria and obesity) independently rated each unique PEM section using the SAM (fig. 1). The patient reviewer, who has an early high school education, participates in the patient advisory board for her primary care clinic and volunteered to help with this study after a brief recruitment presentation by one of the authors (D.S.T.). Reviewers scored each SAM item according to the following original rating scheme: 1 (inadequate), 2 (adequate), or 3 (superior). Items deemed not applicable to a given material were not scored. Responses that differed substantially among the three reviewers (i.e. responses included inadequate and superior or yes and no ratings for the same item; $n = 369/2,857$, 12.9%) were adjudicated to achieve consensus. Adjudicated domain ratings for each PEM section were calculated with the following formula: total points earned/total possible points in that domain. The maximum rating for each domain was 100. Ratings between 70–100 were considered 'superior'; ratings 40–69 were deemed 'adequate', and ratings <40 were considered 'inadequate'. An overall rating for each PEM section was calculated by averaging the 4 domain scores.

Readability Assessment

Reviewers independently determined whether each PEM section was $>$ or \leq a 6th grade reading level. Given that the average American reads at an 8th grade reading level [14], 6th grade reading level is the recommended benchmark for the readability of educational materials in the United States [18]. Sixth grade reading level was defined by presence of short sentences, use of active voice rather than passive voice and most words having 2 syllables or less, consistent with the Simple Measure of Gobbledygook (SMOG) formula of reading level assessment [19]. Readability of each PEM section was determined by consensus. The final overall PEM readability assessment was an average of each of its sections' readability assessments.

Message Content		Visuals/Graphics	
1. Does the material explain the purpose and benefits from the patient's view?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	17. Are there visuals in the document?	<input type="checkbox"/> Yes <input type="checkbox"/> No
2. Is the content limited to a few essential main points that the majority of the target population will benefit from?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	17a. Do the visuals all help communicate the messages in a literal manner (no abstract symbols)?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
3. Are behaviors and skills emphasized rather than just facts?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	17b. Are the visuals culturally relevant and sensitive?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
4. Are readers provided with opportunities for small successes? (i.e., given the chance to set goals for themselves and monitor their progress)	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	17c. Are the visuals easy for readers to follow and understand?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
5. Are key points reviewed at the end of each section/page?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	18. Are there pictures of body parts?	<input type="checkbox"/> Yes <input type="checkbox"/> No
6. Is the material sensitive to cultural differences?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	18a. Are internal body parts or small objects shown in context and in a realistic manner? (i.e., do they help the reader understand the material?)	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
7. Is the new information placed in the context of patients' lives? (i.e., is there a patient story or narrative that helps explain the new information?)	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	19. Are the graphics professional and appropriate for an adult audience?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
8. Are readers told what they should get from the material and what they can do to improve their health? (i.e., is there a clear introduction to the material?)	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	20. Are the graphics free of distracting details that take away from the main idea?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
9. Is the organization of the paragraphs and sentences conducive to easy reading?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	21. Do graphics contribute to the message?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
10. Are instructions broken into easy-to-read parts?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	22. Are examples given for any lists, charts, or diaries that readers are supposed to complete?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
11. Is the material interactive (encourage the patients to write, answer questions, ask questions, cut out forms, etc.)?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior		
Text appearance/typography		Layout and design	
12. Is the font size no smaller than 12–14 point?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	23. Is the cover effectively designed? (i.e., is it appealing and does it convey what topic the material will cover?)	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
13. Is easy-to-read font used? (no fancy script or lettering)	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	24. Are messages organized so they are easy to act on and recall (i.e., text boxes to highlight important points)?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
14. Are bold and underline used instead or ALL CAPS and italics?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	25. Is there a lot of white space (no dense text)?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
15. Are fonts used to promote easy reading? (Dark fonts on light backgrounds are best)	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior	26. Is the text easy for the eye to follow (bullets, paragraph shape: 40–50 characters wide, text boxes)?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior
16. Is sharp contrast and large font used?	<input type="checkbox"/> Inadequate <input type="checkbox"/> Adequate <input type="checkbox"/> Superior		

Fig. 1. SAM domains and items.

Table 1. Characteristics and ratings of CKD PEMs

Source	PEM working title	Target population		Reading level		Content areas and ratings					Overall mean rating	Symbol
		general	minority or ethnic	≤6th grade	>6th grade	Basics of CKD	risk factors for CKD development	risk factors for CKD progression	early complications of CKD	self-management strategies for kidney health		
AKF	Causes_risk factors	*		*			91.7				91.7	■
Kidney School	Module 15: alternatives	*			*				84.7		84.7	■
NKDEP	AA brochure		*	*			84.0				84.0	■
Kidney School	Module 6: anemia	*		*					74.9	82.3	78.6	■
NKF	Anemia	*		*					78.5		78.5	■
NKF	Iron and kidney disease	*		*					78.1		78.1	■
AAKP	Complications	*		*					75.5		75.5	■
Kidney School	Module 12: staying active	*		*						75.4	75.4	■
AKF	Living well	*		*		68.5			82.8	73.0	74.8	■
AKF	Anemia	*		*					74.7		74.7	■
NKF	Nutrition and CKD	*		*						73.9	73.9	■
NKDEP	Explaining CKD test results	*		*		72.9					72.9	■
NKDEP	What is CKD	*			*	73.1				71.4	72.3	■
NKDEP	Nutrition fact sheets	*		*					72.9	71.5	72.2	■
NKDEP	CKD and meds	*		*						71.6	71.6	■
AKF	High blood pressure	*	*	*						70.9	70.9	■
Kidney School	Module 1: basics	*		*		65.8	68.3		78.5		70.9	■
AKF	Facts about CKD	*	*	*		70.1					70.1	■
AKF	Diabetes	*		*						70.1	70.1	■
NKDEP	Nutrition and CKD	*		*						68.6	68.6	□
NKDEP	Sodium	*		*				68.0			68.0	□
NKDEP	CKD for those with diabetes or HTN	*		*			66.5				66.5	□
NKF	About CKD	*	*	*		66.5	65.6	58.2	73.2	68.3	66.4	□
NKDEP	CKD – what does it mean	*		*		64.3				66.5	65.4	□
NKF	BP and kidneys	*	*	*			65.3				65.3	□
NKDEP	Healthy eating for CKD	*		*						64.5	64.5	□
NIDDK	Your kidneys	*			*	62.4	65.0			65.6	64.3	□
NKF	Are you at risk for CKD	*	*	*		63.8	53.4	73.2			63.5	□
DCI	Complications	*		*					62.8		62.8	□
NKF	Diabetes and CKD	*		*			65.2	60.2			62.7	□
AAKP	Kidney beginnings	*		*		63.6	59.6			64.7	62.6	□
NKF	Info about kidneys	*	*	*		52.0	66.0				59.0	□
NIDDK	Proteinuria	*	*		*	58.8					58.8	□
Life Options	CKD info	*		*		58.2	57.4		47.9	71.2	58.7	□
NKF	Staying fit	*		*						57.8	57.8	□
Kidney School	Module 13: heart health	*		*						57.6	57.6	□
NIDDK	high blood pressure	*	*		*					55.1	55.1	□
AAKP	I heart my kidneys	*		*		54.5	56.7			48.0	53.1	□
KUF	Analgesia	*		*			52.1				52.1	□
KUF	About kidneys	*		*		54.0	49.2			52.8	52.0	□
NIDDK	Kidneys-diabetes	*	*	*		61.3	42.5				51.9	□
Uptodate	Diabetes	*		*			51.3				51.3	□
DCI	Strategies	*		*						51.2	51.2	□
Baxter	What is kidney	*		*		47.2				55.1	51.2	□
Baxter	Causes of kidney disease	*		*			51.0				51.0	□
Davita	Progression	*		*				51.0			51.0	□

Table 1 (continued)

Source	PEM working title	Target population		Reading level		Content areas and ratings					Overall mean rating	Symbol
		gen-eral	minor-ity or ethnic	≤6th grade	>6th grade	Basics of CKD	risk factors for CKD develop-ment	risk factors for CKD progression	early compli-cations of CKD	self-man-agement strategies for kidney health		
Uptodate	Chronic kidney disease, the basics	*			*	51.9	49.8	50.8		49.8	50.6	■
Fresenius	Diet and nutrition	*		*					49.5		49.5	■
KCP	Kidney disease	*			*	49.2					49.2	■
Fresenius	Healthy kidneys	*			*	48.6					48.6	■
Davita	Self-management	*			*					48.6	48.6	■
DCI	Kidney disease	*			*	48.3	47.8				48.1	■
Baxter	Diet for CKD	*		*				48.0			48.0	■
Satellite dialysis	Newly diagnosed	*		*		52.3	42.1				47.2	■
Uptodate	High cholesterol	*		*				47.1			47.1	■
ADA	Kidney disease	*			*		47.0				47.0	■
Davita	All stages	*			*	45.8		47.4			46.6	■
Davita	Demographics	*	*		*		46.5				46.5	■
RAI	CKD and diabetes	*		*		50.0	42.9				46.5	■
Baxter	Complications of CKD	*		*					46.3		46.3	■
Davita	Understanding	*			*	46.3					46.3	■
Uptodate	Complications	*		*					46.2		46.2	■
Davita	Preventing		*		*		45.9				45.9	■
ANNA	CKD fact sheet	*			*	47.9		42.9			45.4	■
ANNA	Bone fact sheet	*			*				45.1		45.1	■
Abbott	Improving	*			*				43.9		43.9	■
Davita	Anemia	*			*				43.6		43.6	■
Davita	Complications	*			*				42.9		42.9	■
Fresenius	Kidney disease	*		*			42.3			42.1	42.2	■

NKF = National Kidney Foundation; NKDEP = National Kidney Disease Education Program; NIDDK = National Institute of Diabetes and Digestive and Kidney Disease; AAKP = American Association of Kidney Patients; AKF = American Kidney Fund; ANNA = American Nephrology Nurses Association; KUF = Kidney Urological Foundation; DCI = Dialysis Clinical Incorporated; KCP = Kidney Care Partners; ADA = American Diabetes Association.

□ = Inadequate (0–40%); ■ = adequate (41–69%); ■ = superior (70–100%).

Statistical Analysis

Inter-rater reliability for overall PEM ratings using the SAM was determined by intra-class correlation (ICC). Linear regression was used to determine the impact of readability (> or ≤6th grade reading level) on the mean overall ratings of each PEM section. Stata v11 (StataCorp, College Station, Tex., USA) was used for all analyses.

Results

Characteristics of PEMs

We compiled 69 written CKD PEMs created by 19 different organizations. Characteristics of the PEMs, along with the content areas they covered, the average ratings of each content area and the overall mean ratings are delineated in table 1. Twelve (17%) PEMs targeted African-

American or Latino populations, whereas the remainder targeted the general population. Fourteen (20%) PEMs were created by governmental organizations (National Kidney Disease Education Program, National Institute of Diabetes and Digestive and Kidney Diseases); 30 (42%) were produced by kidney disease advocacy groups (National Kidney Foundation, American Association of Kidney Patients, American Kidney Fund, American Nephrology Nurses Association, Kidney Care Partners, Life Options, Kidney Urological Foundation, American Diabetes Association and Kidney School), and 25 (36%) were developed by large dialysis organizations, pharmaceutical companies or information services companies (Fresenius, DaVita, Dialysis Clinical Incorporated, Renal Advantage Incorporated, Satellite Dialysis, Abbott, Baxter, and Uptodate).

Table 2. Domain ratings for patient educational materials, separated by content area

Content area	n	Domain ratings ± SD				Mean domain rating		
		message content	text appearance	visuals	layout	mean ± SD	min.	max.
Basics of CKD	29	57.7±10.4	66.4±9.5	52.1±14.35	59.0±13.9	58.9±9.1	45.7	73.1
Risk factors for CKD development	29	57.9±10.2	65.8±14.4	49.6±16.9	55.1±8.3	57.0±12.3	42.1	91.7
Risk factors for CKD progression	12	61.2±14.1	74.4±18.2	46.2±18.3	53.5±12.0	58.5±12.0	42.9	84.7
Early complications of CKD	19	60.4±12.0	80.0±19.8	50.0±13.5	59.2±21.7	62.3±15.7	42.88	82.8
Self-management strategies for kidney health	24	64.3±11.99	65.0±11	58.1±19.3	61.5±16.3	62.2±12.3	42.1	82.3
Mean rating		60.3	70.5	51.9	57.7	58.3		

Table 3. The top 5 rated PEMs for each CKD content area

Source	Working title	Characteristics				Domain ratings, %				Average domain rating, %	Symbol
		target population		reading level		message content	text appearance	visuals	layout		
		gen-eral	minority or ethnic	≤6th grade	>6th grade						
<i>Content area: basics of CKD</i>											
NKDEP	What is CKD	*		*		57.6	93.3	66.7	75.0	73.1	■
NKDEP	Explaining kidney test results	*		*		64.6	66.7	77.8	83.3	72.9	■
AKF	CKD facts	*	*	*		75.8	66.7	71.4	66.7	70.1	■
AKF	Living well with CKD	*		*		78.8	66.7	61.9	66.7	68.5	□
NKF	About CKD	*		*		57.6	66.7	66.7	75.0	66.5	□
<i>Content area: risk factors for CKD development</i>											
AKF	Kidney disease: what do I need to know?	*		*		84.8	100.0	90.5	91.7	91.7	■
NKDEP	What AA with DM or HTN need to know		*	*		72.8	100.0	71.4	91.7	84.0	■
Fresenius	Kidney School: basics of CKD	*			*	73.3	66.7	66.7	66.7	68.3	□
NKDEP	For people with diabetes or HTN	*		*		60.6	66.7	55.6	83.3	66.5	□
NKF	Info about kidneys	*		*		66.7	66.7	55.6	75.0	66.0	□
<i>Content area: risk factors for CKD Progression</i>											
Kidney School	Alternatives for your health	*			*	81.8	100.0	90.5	66.7	84.7	■
NKF	Are you at risk for CKD	*	*	*		60.1	93.3	55.6	83.3	73.2	■
NKDEP	Sodium: risk factors for CKD	*		*		63.6	100.0	58.3	50.0	68.0	□
NKF	Diabetes and CKD	*		*		54.5	66.7	61.1	58.3	60.2	□
NKF	About CKD	*	*	*		60.6	66.7	55.6	50.0	58.2	□
<i>Content area: complications of CKD</i>											
AKF	Living well with CKD	*		*		72.7	100.0	66.7	91.7	82.8	■
NKF	Anemia and CKD	*		*		66.7	100.0	55.6	91.7	78.5	■
Kidney School	Basics of CKD	*		*		84.8	100.0	55.6	75.0	78.5	■
NKF	Iron and kidney disease	*		*		63.6	100.0	57.1	91.7	78.1	■
AAKP	Complications of CKD	*		*		70.0	100.0	57.1	75.0	75.5	■
<i>Content area: self-management strategies for kidney health</i>											
Kidney School	Anemia	*		*		84.8	66.7	94.4	83.3	82.3	■
Kidney School	Staying active with CKD	*		*		84.8	66.7	83.3	66.7	75.4	■
NKF	Nutrition and CKD	*		*		72.7	86.7	61.1	75.0	73.9	■
AKF	Living well with CKD	*		*		69.7	66.7	72.2	83.3	73.0	■
NKDEP	CKD and medications	*		*		69.7	66.7	66.7	83.3	71.6	■

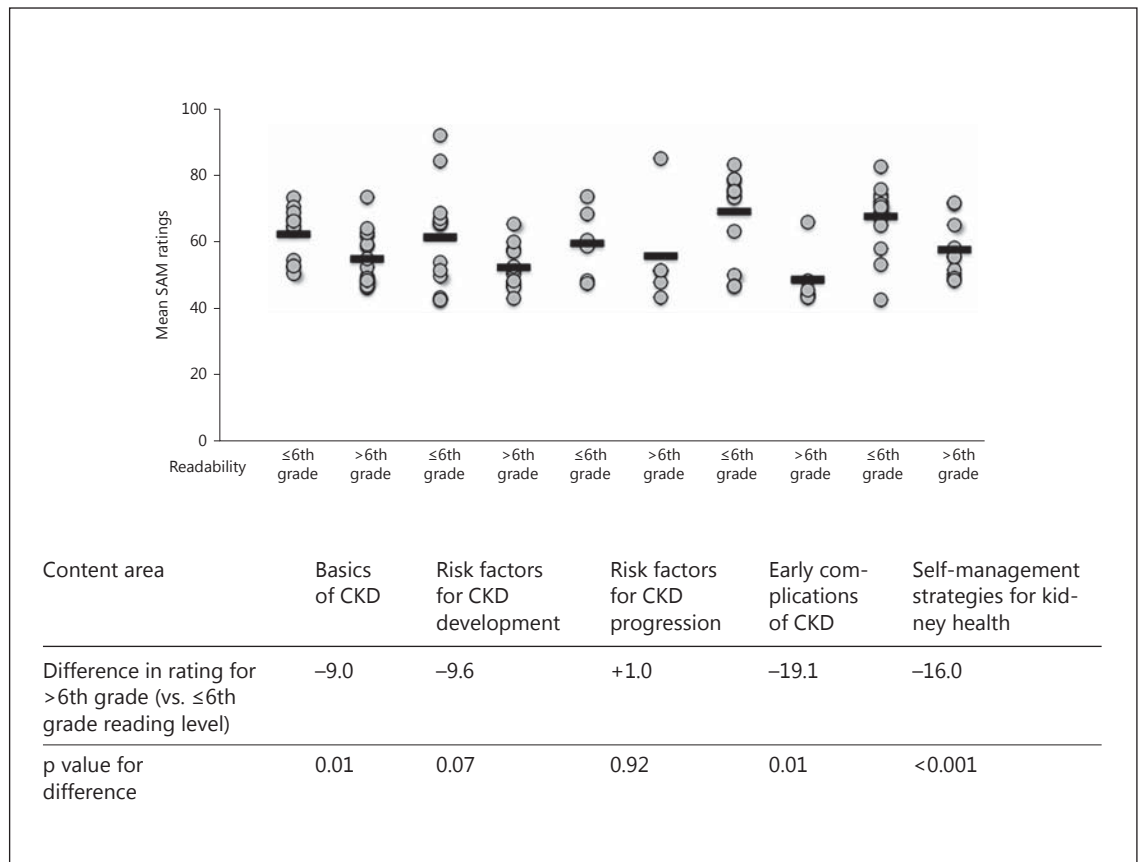


Fig. 2. Association of readability with ratings, by content area. p values for difference in ratings by readability were determined by linear regression.

Inter-Rater Reliability and Ratings of PEMs

ICC for all 3 reviewers was 0.60. ICC for the 2 physician raters was 0.75. This difference was driven primarily by the message content domain of the SAM, for which the patient reviewer rated materials on average 13 points higher than the physician reviewers ($p < 0.001$).

Using the adjudicated responses, most (79%) PEM sections were deemed 'adequate' with an overall rating between 40 and 69. Approximately 20% of CKD PEM sections were considered 'superior', with an overall rating between 70–100. No CKD PEM section was deemed 'inadequate'. The overall mean PEM rating was 58.3, with modest differences across content areas. Mean ratings were highest for the PEM sections that focused on early complications of CKD (62.3, SD = 15.7); ratings were lowest for the PEM sections that concentrated on risk factors for CKD development (57.0, SD = 2.3; table 2). Table 3 illustrates the detailed performance data of the top 5 rated PEMs by content area.

With regard to the domains captured by the SAM items, only the text appearance/typography domain had a mean rating in the 'superior' range (70.5). The other three domains had mean ratings within the 'adequate' range: message content, 60.3; visuals/graphics 51.9, and layout/design, 57.7 (table 2).

Reading Level of PEMs and Impact on Ratings

Nearly one half of the PEMs (30/69) were determined to have a reading level higher than that of a 6th grade student. A higher than 6th grade reading level (compared to ≤6th grade) was associated with an 11.7-point decrease ($p < 0.01$) in overall mean PEM ratings. Differences in ratings between PEMs of higher and lower reading levels ranged from +1 point ($p = 0.92$) in the PEM sections that focused on risk factors for CKD progression to -19.1 points ($p = 0.01$) in the sections that discussed complications of CKD (fig. 2).

Discussion

This evaluation of printed English PEMs for patients with CKD demonstrates variable suitability of existing materials, with a mean rating of 58.3/100 and an overall range of 42.2–91.7, as determined by the validated SAM instrument. While no educational materials were deemed ‘inadequate’ and all materials were at least considered ‘adequate’, only 20% received a ‘superior’ rating. Ratings (and variability in ratings) of CKD educational materials were comparable across the 5 different content areas that we evaluated. These results are similar to scores that have been published from evaluations of PEMs for other medical conditions, suggesting high availability of health-related PEMs that are decent or good enough, but relatively few that are outstanding [15–17, 20, 21].

Physicians and patients may differ in what they think is important to communicate (and how). In our study, the patient reviewer consistently rated the patient centeredness of the message content more highly than the physician reviewers, with concomitant lower but non-statistically significant differences in ratings of the other SAM domains (typography, visuals and layout/design). Adjudication of results may have thus resulted in lower ratings for the message content domain, suggesting that educational materials may actually convey information more frequently in a patient-centered, culturally appropriate manner than believed by clinicians or depicted in this study. Another explanation could be that the clinician reviewers had higher standards for patient-centered content because of prior exposure to patient-centered PEMs for other diseases. Nevertheless, most PEMs that achieved a ‘superior’ rating exhibited similar strengths, suggesting that both the patient and clinician reviewers shared similar ideals of what makes an ideal PEM.

One characteristic shared by ‘superior’ PEMs was providing health information in the context of a patient’s experience. One highly rated PEM dedicated to early complications of CKD uses first-person vignettes to present anemia in a patient-centered fashion: ‘I learned early that I’m the one who knows my body best. I knew something wasn’t right when I constantly felt tired and worn out. I talked to my doctor and found out I was anemic. ... Anemia is explained in the section below.’ In contrast, a less highly rated PEM about anemia documented similar symptoms without the accompanying story: ‘Anemia happens when your body is not making enough red blood cells. ... Symptoms of anemia can include the following: feeling weak, feeling tired or fatigued, dizziness...’

Highly rated PEMs also included language, tables, and charts that stimulate readers to interact with the material, encouraging them to participate in their own CKD care. Motivating language in ‘superior’ PEMs is positive, such as in the following example from a pamphlet that discusses the basics of CKD: ‘You may be wondering what you can do now to keep your kidneys as healthy as possible. With early treatment, you may be able to help keep your CKD from getting worse.’ By contrast, ‘adequate’ PEMs use neutral language with a less optimistic feel, such as the following example: ‘Have you been told that you have kidney problems or that laboratory tests show your kidney function is not normal? If so, you may be ... at risk for ... kidney failure.’ Charts and tables that accompany the optimistic language are essential to help patients visualize and internalize the topics covered. For example, two ‘superior’ materials encouraged patients to write down questions for their providers and one included a section for action planning with a fill-in-the-blank paragraph.

Inclusion of such patient-centered and behavior change-oriented content is the hallmark of an ideal educational material, and is an important PEM characteristic about which clinicians should be aware. Patient-centered content is of particular importance, as qualitative data suggest that patients want practical and specific information to support their medical knowledge and self-care efforts, rather than general advice from experts [22]. In addition, patient-centered care and patient-centered educational efforts, both central to the Chronic Care Model [23], are associated with improved patient self-efficacy and improved outcomes [24]. Patients also benefit from learning from other patient experiences. For example, provision of an asthma workbook to patients that included narrative vignettes informed by actual patients has been associated with improvement in patient self-efficacy and self-management [25, 26]. Action planning – making very specific goals and writing them down – is a cornerstone of behavior change science. Studies among patients with chronic diseases have demonstrated that action planning increases the likelihood that patients actually reach their goals [27–29]. PEMs that have incorporated these concepts may be of most clinical utility for patients and providers when discussing CKD.

With respect to graphics, while most of the materials we assessed had visuals/pictures that were deemed professional and easy to understand, they often did not contribute to the overall message. Educational theory suggests that presenting congruent information in multiple formats increases comprehension [30]. The importance of pictures for enhanced patient understanding of the

risks/benefits of medication treatment [31] and clinical research endeavors [32], as well as comprehension of medical illnesses [33] has been well documented. Graphics can play a particularly important role in shaping patient understanding of kidney disease since the concepts of blood pressure and glomerular filtration can be difficult to explain with words. Providers may find PEMs with pictures and explanatory captions to explain CKD concepts most useful as an adjunct to their discussions with patients.

Approximately one half of the PEMs we evaluated had a reading level at or below that of a 6th grade student. There is considerable evidence that low health literacy is associated with poor health outcomes among patients with chronic diseases [34], including many associated with CKD, such as diabetes [35, 36], congestive heart failure [37] and hypertension [38]. More recently, this has been recognized among individuals with ESRD, in whom low health literacy is associated with decreased access to kidney transplantation and increased mortality [39–41]. The relationship between low literacy and adverse health outcomes is likely present among individuals with CKD as well, but it has not yet been extensively explored. Many mechanisms exist by which limited health literacy can influence kidney and overall health, including a negative impact on patient knowledge/beliefs [42]. As an example, a recent study among patients with CKD and diabetes demonstrated a significant and independent association between patient knowledge about their blood pressure goal and achievement of systolic blood pressure <130 mm Hg [43]. In addition to knowledge, health literacy affects other constructs that are key to supporting patient self-care and improving health outcomes, such as motivation for behavior change, problem-solving ability, and self-efficacy [44]. Use of low-literacy CKD PEMs by clinicians for all patients may not only ensure patient understanding but also increase patient self-efficacy for CKD self-management. Indeed, we found an association between lower reading level and higher PEM ratings, suggesting that materials with shorter sentences/words may communicate their message more clearly, leading to more patient-centered content.

This study is not without its limitations. We did not have information about how printed PEMs were developed or their original intent or purpose. Additionally, we did not evaluate other delivery media such as web-based video or audio. While Internet-based communication is certainly gaining relevance, we focused our evaluation on printed materials that were readily available for providers to give to patients to reinforce verbally delivered CKD

education. Printed educational materials have been demonstrated to enhance patient knowledge and understanding of health conditions in randomized controlled trials [33, 45, 46]. They also offer a number of advantages over web-based tools, such as consistency/reliability, portability, and low cost, which maintain their relevancy in an ever-changing world of health communication and education. The SAM is a validated instrument to assess the content and presentation of printed documents but it does not capture all of the important characteristics of a material designed for health education. For example, SAM items do not assess how a reader interacts or uses a given material, the length of the material, the time it takes an individual to read through a PEM, or the number of concepts covered. The SAM also does not include questions that are specifically about kidney disease, and it has not been validated for use by patients. Our analysis, similar to the development of quality measures, systematic reviews and scientific peer review, was based on a small number of well-informed raters, allowing some possibility of bias. However, we were explicit in including a patient rater in our evaluation process, which is novel, and arguably the most important perspective of a PEM's suitability and readability. While the inter-rater reliability among the physicians was consistent or better than that documented by prior studies using the SAM [15, 21], the ICC was lower when including patient responses, leading us to adjudicate differences to achieve consensus. Future studies about this topic should be sure to include patients or other end users (i.e. family members, caregivers). Lastly, this analysis does not examine the association of suitability ratings or readability with actual patient understanding, self-efficacy for self-management, or clinical outcomes. Such a study is an essential next step.

The findings from this study have important practice implications. Health care providers are increasingly responsible to empower individuals to participate in their own healthcare. As such, providers charged with the responsibility of educating patients with and at high-risk for CKD need to be aware of strengths and limitations in existing PEMs pertaining to kidney disease. Clinicians could consider preferentially using PEMs written at lower readability levels, as well as those that incorporate patient centeredness, opportunities for patient interaction and motivational language, given our finding that such educational materials achieved higher ratings. This may lead to higher patient awareness of kidney disease and greater patient engagement in CKD self-management, thereby leading to improved health outcomes among individuals with and at risk for CKD.

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