UCSF

UC San Francisco Previously Published Works

Title

Assessment of Printed Patient-Educational Materials for Chronic Kidney Disease

Permalink

https://escholarship.org/uc/item/0q41j4kj

Journal

American Journal of Nephrology, 38(3)

ISSN

0250-8095

Authors

Tuot, Delphine S Davis, Elizabeth Velasquez, Alexandra et al.

Publication Date

2013

DOI

10.1159/000354314

Peer reviewed



Am J Nephrol. Author manuscript; available in PMC 2014 August 21.

Published in final edited form as:

Am J Nephrol. 2013; 38(3): 184-194. doi:10.1159/000354314.

Assessment of printed patient-educational materials for chronic kidney disease

Delphine S Tuot, MDCM, MAS¹, Elizabeth Davis, MD², Alexandra Velasquez, BS¹, Tanushree Banerjee, PhD², and Neil R Powe, MD, MPH, MBA^{2,3}

¹Division of Nephrology, University of California San Francisco

²Department of Medicine, University of California San Francisco

³Center for Vulnerable Populations at San Francisco General Hospital, San Francisco, CA

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.

Keywords

chronic kidney disease; health literacy; patient education materials

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

Correspondence: Delphine S. Tuot. San Francisco General Hospital, 1001 Potrero Avenue. Bldg 100, Room 342. San Francisco, CA. 94110. Telephone: 415.206.3784, Fax: 415.282.8182, Delphine.tuot@ucsf.edu.

Disclosures:

None of the authors have any financial disclosures or conflicts of interest to report.

(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] Implementation 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 less than 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 webbased 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 (DST, nephrologist; ED, general internist; JR, 54yo Caucasian patient followed in primary care with proteinuria and obesity) independently rated each unique PEM section using the SAM. (Figure 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 (DST). 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=369/2857, 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 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 conensus. The final overall PEM readability assessment was an average of each of its sections' readability assessments.

Statistical Analysis

Inter-rater reliability for overall PEM ratings using the SAM was determined by intra-class correlation. 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 version 11 (StataCorp, College Station, Texas 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 [NKDEP], National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK]); 30 (42%) were produced by kidney disease advocacy

groups (National Kidney Foundation [NKF], American Association of Kidney Patients [AAKP], American Kidney Fund [AKF], American Nephrology Nurses Association [ANNA], Kidney Care Partners [KCP], Life Options, Kidney Urological Foundation [KUF], American Diabetes Association [ADA] 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).

Inter-rater reliability and Ratings of PEMs

Intra-class correlation (ICC) for all three reviewers was 0.60. ICC for the two 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 40–69. 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 regards 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 6^{th} grade student. A higher than 6^{th} grade reading level (compared to 6^{th} 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. (Figure 2)

Discussion

This evaluation of printed English patient educational materials 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 to 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 a PEM patient centered.

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 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] Another cornerstone of behavior change science is action planning -- making very specific goals and writing them down. 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 < 130mmHg.[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 selfefficacy.[44] Use of low-literacy CKD patient educational materials 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 nor 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 everchanging 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.

Acknowledgments

Funding Sources/Support of Sponsor: This work is supported by the R34DK093992 and Dr. Tuot is supported by K23DK094850, both from the National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD.

References

- Coresh J, Byrd-Holt D, Astor BC, Briggs JP, Eggers PW, Lacher DA, Hostetter TH. Chronic kidney disease awareness, prevalence, and trends among u.S. Adults, 1999 to 2000. J Am Soc Nephrol. 2005; 16:180–188. [PubMed: 15563563]
- Go AS, Chertow GM, Fan D, McCulloch CE, Hsu CY. Chronic kidney disease and the risks of death, cardiovascular events, and hospitalization. N Engl J Med. 2004; 351:1296–1305. [PubMed: 15385656]
- 3. Barrett BJ. Applying multiple interventions in chronic kidney disease. Semin Dial. 2003; 16:157–164. [PubMed: 12641881]
- 4. Sarnak MJ, Greene T, Wang X, Beck G, Kusek JW, Collins AJ, Levey AS. The effect of a lower target blood pressure on the progression of kidney disease. Long-term follow-up of the modification of diet in renal disease study. Ann Intern Med. 2005; 142:342–351. [PubMed: 15738453]
- Nissenson AR, Collins AJ, Hurley J, Petersen H, Pereira BJ, Steinberg EP. Opportunities for improving the care of patients with chronic renal insufficiency: Current practice patterns. J Am Soc Nephrol. 2001; 12:1713–1720. [PubMed: 11461944]
- 6. Costantini L, Beanlands H, McCay E, Cattran D, Hladunewich M, Francis D. The self-management experience of people with mild to moderate chronic kidney disease. Nephrol Nurs J. 2008; 35:147–155. quiz 156. [PubMed: 18472683]
- Plantinga LC, Tuot DS, Powe NR. Awareness of chronic kidney disease among patients and providers. Adv Chronic Kidney Dis. 2010; 17:225–236. [PubMed: 20439091]
- 8. Tuot DS, Plantinga LC, Hsu CY, Jordan R, Burrows NR, Hedgeman E, Yee J, Saran R, Powe NR. Chronic kidney disease awareness among individuals with clinical markers of kidney dysfunction. Clin J Am Soc Nephrol. 2011; 6:1838–1844. [PubMed: 21784832]
- Wright Nunes JA, Wallston KA, Eden SK, Shintani AK, Ikizler TA, Cavanaugh KL. Associations among perceived and objective disease knowledge and satisfaction with physician communication in patients with chronic kidney disease. Kidney Int. 2011; 80:1344–1351. [PubMed: 21832984]
- Hostetter TH, Lising M. National kidney disease education program. J Am Soc Nephrol. 2003; 14:S114–116. [PubMed: 12819314]
- 11. Kutner, M.; Greenberg, E.; Jin, Y.; Paulsen, C. The health literacy of america's adults: Results from the 2003 national assessment of adult literacy (NCES 2006-483). Washington DC: National CEnter for Educational Statistics, US Department of Education; 2006.
- Fraser SD, Roderick PJ, Casey M, Taal MW, Yuen HM, Nutbeam D. Prevalence and associations of limited health literacy in chronic kidney disease: A systematic review. Nephrol Dial Transplant. 2013; 28:129–137. [PubMed: 23222414]

13. Calderon JL, Zadshir A, Norris K. Structure and content of chronic kidney disease information on the world wide web. Barriers to public understanding of a pandemic. Nephrol News Issues. 2004; 18:76, 78–79, 81–74. [PubMed: 15551616]

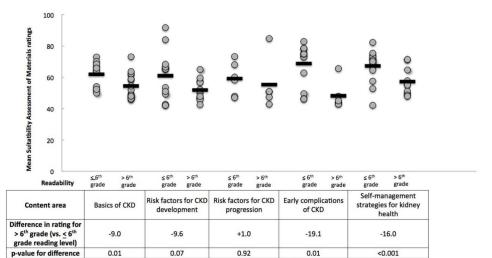
- 14. Doak, CC.; Doak, LG.; Root, JH. Teaching patients with low literacy skills. 2. Philadelphia: J.B. Lippincott; 1996.
- Taylor-Clarke K, Henry-Okafor Q, Murphy C, Keyes M, Rothman R, Churchwell A, Mensah GA, Sawyer D, Sampson UK. Assessment of commonly available education materials in heart failure clinics. J Cardiovasc Nurs. 2012; 27:485–494. [PubMed: 21743339]
- Lee TW, Kang SJ, Kim HH, Woo SR, Kim S. suitability and readability assessment of printed educational materials on hypertension. J Korean Acad Nurs. 2011; 41:333–343. [PubMed: 21804342]
- 17. Hoffmann T, Ladner Y. Assessing the suitability of written stroke materials: An evaluation of the interrater reliability of the suitability assessment of materials (sam) checklist. Top Stroke Rehabil. 2012; 19:417–422. [PubMed: 22982829]
- 18. Kirsch, I.; Jungeblut, A.; Jenkins, L. Adult literacy in america: A first look at the results of the national adult literacy survey. Department of Education; Washington, DC: 1993.
- Wang LW, Miller MJ, Schmitt MR, Wen FK. Assessing readability formula differences with written health information materials: Application, results, and recommendations. Res Social Adm Pharm. 2012
- Fagerlin A, Rovner D, Stableford S, Jentoft C, Wei JT, Holmes-Rovner M. Patient education materials about the treatment of early-stage prostate cancer: A critical review. Ann Intern Med. 2004; 140:721–728. [PubMed: 15126256]
- Vallance JK, Taylor LM, Lavallee C. Suitability and readability assessment of educational print resources related to physical activity: Implications and recommendations for practice. Patient Educ Couns. 2008; 72:342–349. [PubMed: 18450409]
- 22. Seligman HK, Wallace AS, DeWalt DA, Schillinger D, Arnold CL, Shilliday BB, Delgadillo A, Bengal N, Davis TC. Facilitating behavior change with low-literacy patient education materials. Am J Health Behav. 2007; 31 (Suppl 1):S69–78. [PubMed: 17931139]
- Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: Translating evidence into action. Health Aff (Millwood). 2001; 20:64–78. [PubMed: 11816692]
- 24. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: The chronic care model, part 2. JAMA. 2002; 288:1909–1914. [PubMed: 12377092]
- Mancuso CA, Sayles W, Robbins L, Allegrante JP. Novel use of patient-derived vignettes to foster self-efficacy in an asthma self-management workbook. Health Promot Pract. 2010; 11:44–53.
 [PubMed: 18403749]
- Mancuso CA, Sayles W, Allegrante JP. Randomized trial of self-management education in asthmatic patients and effects of depressive symptoms. Ann Allergy Asthma Immunol. 2010; 105:12–19. [PubMed: 20642198]
- 27. Bischoff EW, Hamd DH, Sedeno M, Benedetti A, Schermer TR, Bernard S, Maltais F, Bourbeau J. Effects of written action plan adherence on copd exacerbation recovery. Thorax. 2011; 66:26–31. [PubMed: 21037270]
- Naik AD, Palmer N, Petersen NJ, Street RL Jr, Rao R, Suarez-Almazor M, Haidet P. Comparative effectiveness of goal setting in diabetes mellitus group clinics: Randomized clinical trial. Arch Intern Med. 2011; 171:453–459. [PubMed: 21403042]
- 29. Bodenheimer T, Handley MA. Goal-setting for behavior change in primary care: An exploration and status report. Patient Educ Couns. 2009; 76:174–180. [PubMed: 19560895]
- 30. Paivio, A. Mental representations: A dual coding approach. New York: Clarendon Press; 1986.
- 31. Hawley ST, Zikmund-Fisher B, Ubel P, Jancovic A, Lucas T, Fagerlin A. The impact of the format of graphical presentation on health-related knowledge and treatment choices. Patient Educ Couns. 2008; 73:448–455. [PubMed: 18755566]
- 32. Tait AR, Voepel-Lewis T, Zikmund-Fisher BJ, Fagerlin A. The effect of format on parents' understanding of the risks and benefits of clinical research: A comparison between text, tables, and graphics. J Health Commun. 2010; 15:487–501. [PubMed: 20677054]

33. You WB, Wolf MS, Bailey SC, Grobman WA. Improving patient understanding of preeclampsia: A randomized controlled trial. Am J Obstet Gynecol. 2012; 206:431, e431–435. [PubMed: 22542120]

- Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: An updated systematic review. Ann Intern Med. 2011; 155:97–107. [PubMed: 21768583]
- 35. Schillinger D, Barton LR, Karter AJ, Wang F, Adler N. Does literacy mediate the relationship between education and health outcomes? A study of a low-income population with diabetes. Public Health Rep. 2006; 121:245–254. [PubMed: 16640146]
- Schillinger D, Grumbach K, Piette J, Wang F, Osmond D, Daher C, Palacios J, Sullivan GD, Bindman AB. Association of health literacy with diabetes outcomes. JAMA. 2002; 288:475–482. [PubMed: 12132978]
- 37. Peterson PN, Shetterly SM, Clarke CL, Bekelman DB, Chan PS, Allen LA, Matlock DD, Magid DJ, Masoudi FA. Health literacy and outcomes among patients with heart failure. JAMA. 2011; 305:1695–1701. [PubMed: 21521851]
- 38. Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. Arch Intern Med. 1998; 158:166–172. [PubMed: 9448555]
- 39. Cavanaugh KL, Wingard RL, Hakim RM, Eden S, Shintani A, Wallston KA, Huizinga MM, Elasy TA, Rothman RL, Ikizler TA. Low health literacy associates with increased mortality in esrd. J Am Soc Nephrol. 2010; 21:1979–1985. [PubMed: 20671215]
- 40. Grubbs V, Gregorich SE, Perez-Stable EJ, Hsu CY. Health literacy and access to kidney transplantation. Clin J Am Soc Nephrol. 2009; 4:195–200. [PubMed: 19056617]
- 41. Green JA, Mor MK, Shields AM, Sevick MA, Arnold RM, Palevsky PM, Fine MJ, Weisbord SD. Associations of health literacy with dialysis adherence and health resource utilization in patients receiving maintenance hemodialysis. Am J Kidney Dis. 2013; 62:73–80. [PubMed: 23352380]
- 42. Osborn CY, Paasche-Orlow MK, Bailey SC, Wolf MS. The mechanisms linking health literacy to behavior and health status. Am J Health Behav. 2011; 35:118–128. [PubMed: 20950164]
- 43. Wright-Nunes JA, Luther JM, Ikizler TA, Cavanaugh KL. Patient knowledge of blood pressure target is associated with improved blood pressure control in chronic kidney disease. Patient Educ Couns. 2012; 88:184–188. [PubMed: 22459637]
- 44. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. JAMA. 2002; 288:2469–2475. [PubMed: 12435261]
- 45. Partin MR, Nelson D, Radosevich D, Nugent S, Flood AB, Dillon N, Holtzman J, Haas M, Wilt TJ. Randomized trial examining the effect of two prostate cancer screening educational interventions on patient knowledge, preferences, and behaviors. J Gen Intern Med. 2004; 19:835–842. [PubMed: 15242468]
- 46. Muthusamy AD, Leuthner S, Gaebler-Uhing C, Hoffmann RG, Li SH, Basir MA. Supplemental written information improves prenatal counseling: A randomized trial. Pediatrics. 2012; 129:e1269–1274. [PubMed: 22492766]

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

Figure 1. Suitability of Assessment of Materials Domains and Items.



NOTE: p-values for difference in ratings by readability are determined by linear regression

Figure 2. Association of readability with ratings, by content area.

Table 1

Characteristics of chronic kidney disease (CKD) patient educational materials (PEMs).

	Symbol														
	Ovearll mean PEM rating	<i>L</i> .19	84.7	84.0	78.6	78.5	78.1	75.5	75.4	74.8	74.7	73.9	72.9	72.3	72.2
	Self-management strategies for kidney health				82.3				75.4	73.0		73.9		71.4	71.5
atings	Early complications of CKD				74.9	78.5	78.1	75.5		82.8	7.4.7				72.9
Content areas and ratings	Risk factors for CKD Progression		84.7												
	Risk facotrs for CKD Development	7.16		84.0											
	Basics of CKD									68.5			72.9	73.1	
level	> 6th grade		*											*	
Reading level	6th grade	*		*	*	*	*	*	*	*	*	*	*		*
Target population	Minority or Ethnic			*											
Tar	General	46-	*		*	*	₩	₩	46-	46-	₩	*	*	*	*
	PEM working title	Causes_risk factors	Module 15: Alternatives	AA brochure	Module 6: Anemia	Anemia	Iron and kidney disease	Complications	Module 12: Staying active	Living well	Anemia	Nutrition and CKD	Explaining CKD test results	What is CKD	Nutrition fact sheets
	Source	AKF	Kidney school	NKDEP	Kidney school	NKF	NKF	AAKP	Kidney school	AKF	AKF	NKF	NKDEP	NKDEP	NKDEP

Ovearll mean PEM rating 71.6 70.9 70.9 70.1 70.1 9.89 0.89 66.5 66.4 65.4 65.3 64.5 64.3 63.5 62.8 Self-management strategies for kidney health 71.6 9.89 64.5 70.9 70.1 68.3 66.5 Early complications of CKD 78.5 73.2 65.6 62.8 Content areas and ratings Risk factors for CKD Progression 0.89 58.2 73.2 Risk facotrs for CKD Development 68.3 66.5 9.59 65.3 65.0 53.4 Basics of CKD 65.8 70.1 66.5 64.3 62.4 63.8 > 6th grade 6th grade Minority or Ethnic CKD for those with diabetes or HTN Are you at risk for CKD CKD-what does it mean Healthy eating for CKD PEM working title High blood pressure Nutrition and CKD Facts about CKD Module 1: Basics BP and Kidneys CKD and meds Your kidneys Diabetes Sodium Kidney school NKDEP NKDEP NIDDK NKDEP NKDEP NKDEP Source NKDEP AKF AKF AKF NKF NKF NKF DCI

Ovearll mean PEM rating 62.7 62.6 59.0 58.8 58.7 57.8 57.6 55.1 53.1 52.1 52.0 51.9 51.3 51.2 51.2 Self-management strategies for kidney health 64.7 71.2 48.0 51.2 57.8 57.6 55.1 52.8 55.1 Early complications of CKD 47.9 Content areas and ratings Risk factors for CKD Progression 60.2 Risk facotrs for CKD Development 65.2 59.6 0.99 26.7 49.2 42.5 51.3 57.4 52.1 Basics of CKD 54.0 63.6 52.0 58.8 58.2 54.5 61.3 47.2 > 6th grade 6th grade Minority or Ethnic Module 13: Heart health PEM working title Diabetes and CKD highblood pressure Kidney beginnings Info about kidneys I heart my kidneys Kidneys-diabetes About kidneys What is kidney Staying Fit Ckd-info Diabetes Kidney school Life options NIDDK Uptodate NIDDK NIDDK Source AAKP AAKP Baxter NKF NKF KUF NKF KUF DCI

	Symbol	-	-	-	-	-	-	-	-	•	-	-	-	-	-	-
	Ovearll mean PEM rating	51.0	51.0	50.6	49.5	49.2	48.6	48.6	48.1	48.0	47.2	47.1	47.0	46.6	46.5	46.5
	Self-management strategies for kidney health			49.8				48.6								
atings	Early complications of CKD				49.5											
Content areas and ratings	Risk factors for CKD Progression		51.0	50.8						48.0		47.1		47.4		
	Risk facotrs for CKD Development	51.0		49.8					47.8		42.1		47.0		46.5	42.9
	Basics of CKD			51.9		49.2	48.6		48.3		52.3			45.8		50.0
g level	> 6th grade		**	**		*	**	46	**				**	*	**	
Reading level	6th grade	*			*					*	*	*				*
Target population	Minority or Ethnic														*	
Tar	General	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*
	PEM working title	Causes of kidney disease	Progression	Chronic kidney disease, The Basics	Diet and Nutrition	Kidney disease	Healthy kidneys	Self-management	Kidney disease	Diet for CKD	Newly diagnosed	High cholesterol	Kidney disease	All stages	Demographics	CKD and diabetes
	Source	Baxter	Davita	Uptodate	Fresenius	KCP	Fresenius	Davita	DCI	Baxter	Satellite dialysis	Uptodate	ADA	Davita	Davita	RAI

	Symbol	•	-	•	•	•	-	•	•	•	•
	Ovearll mean PEM rating	46.3	46.3	46.2	45.9	45.4	45.1	43.9	43.6	42.9	42.2
	Self-management strategies for kidney health										42.1
atings	Early complications of CKD	46.3		46.2			45.1	43.9	43.6	42.9	
Content areas and ratings	Risk factors for CKD Progression					42.9					
	Risk facotrs for CKD Development				45.9						42.3
	Basics of CKD		46.3			47.9					
g level	> 6th grade		*		90-	*	*	**	*	*	
Reading level	6th grade	*		*							*
Target population	Minority or Ethnic				*						
Tary	General	*	16	*		₩	₩	46	*	*	*
	PEM working title	Complications of CKD	Understanding	Complications	Preventing	Ckd fact sheet	Bone fact sheet	Improving	Anemia	Complications	Kidney Disease
	Source	Baxter	Davita	Uptodate	Davita	ANNA	ANNA	Abbott	Davita	Davita	Fresenius

Abbreviations: 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; AKF=American Linical Incorporated; KCP=Kidney Care Partners; ADA=American Diabetes Association

Page 16

Note: Symbols represent Superior, Adequate or Inadequate ratings.

0-40% • 41-69% • 70-100% •

Table 2

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

Composed Augo	2		Domain ratings (SD)	(SD)		Mean domain rating	main rat	gu
Content Area	_	Message content	Message content Text appearance Visuals Layout mean (SD) Min Max	Visuals	Layout	mean (SD)	Min	Max
Basics of CKD	29	57.7 (10.4)	66.4 (9.5)	52.1 (14.35)	52.1 (14.35) 59.0 (13.9) 58.9 (9.1) 45.7	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)	49.6 (16.9) 55.1 (18.3) 57.0 (12.3) 42.1	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)	46.2 (18.3) 53.5 (12.0) 58.5 (12.0) 42.9 84.7	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)	50.0 (13.5) 59.2 (21.7) 62.3 (15.7) 42.88	62.3 (15.7)	42.88	82.8
Self-management strageies for kidney health 24	24	64.3 (11.99)	65.0 (11)	58.1 (19.3)	58.1 (19.3) 61.5 (16.3) 62.2 (12.3) 42.1	62.2 (12.3)	42.1	82.3
Mean ratmg		60.3	70.5	51.9	27.7	58.3		

Table 3

Tuot et al.

The top 5 rated PEMs for each CKD content area.

		Symbol					•	•		•		•	•	•		
Avo	Domain Pating	(%)		73.1	72.9	70.1	68.5	66.5		91.7	84.0	68.3	66.5	0.99		84.7
	Lovout	Layout		75.0	83.3	66.7	66.7	75.0		91.7	91.7	66.7	83.3	75.0		66.7
	Vienole	v isuais		66.7	77.8	71.4	61.9	66.7		90.5	71.4	66.7	55.6	55.6		90.5
Domain ratings (%)	Tort onnocenous	rext appearance		93.3	66.7	66.7	66.7	66.7		100.0	100.0	66.7	66.7	66.7		100.0
	Mossogo content	Message content	æ	57.6	64.6	75.8	78.8	57.6	Development	84.8	72.8	73.3	9.09	66.7	Progression	81.8
	g level	> 6th grade	Content area: Basics of CKD						Content area: Risk factors for CKD Development			*			Content area: Risk factors for CKD Progression	*
istics	Reading level	6th grade	Content are	*	*	*	*	*	t area: Risk fac	*	*		*	*	ıt area: Risk fa	
Characteristics	Target population	Minority or Ethnic				*			Conten		*				Conter	
	Tar	General		*	*	*	*	*		*		*	*	*		*
	Working title			What is CKD	Explaining kidney test results	CKD facts	Living well with CKD	About CKD		Kidney Disease: What do I need to know?	What AA with DM or HTN need to know	Kidney School: Basicsof CKD	For people with diabetes or HTN	Info about kidneys		Alternatives for your health
	Source			NKDEP	NKDEP	AKF	AKF	NKF		AKF	NKDEP	Fresenius	NKDEP	NKF		Kidney School

Symbol Avg Domain Rating (%) 73.2 82.8 0.89 73.9 73.0 60.2 58.2 78.5 78.5 78.1 75.5 82.3 75.4 Layout 50.0 50.0 91.7 75.0 91.7 75.0 83.3 83.3 58.3 91.7 83.3 2.99 75.0 Visuals 58.3 55.6 55.6 55.6 83.3 57.1 94.4 61.1 72.2 55.6 2.99 61.1 57.1 Domain ratings (%) Text appearance 100.0 100.0 100.0 100.0 100.0 100.0 93.3 2.99 2.99 66.7 86.7 2.99 66.7 Message content Content area: Self-managmenet strategies for kidney health 63.6 54.5 9.09 2.99 84.8 63.6 70.0 84.8 84.8 72.7 69.7 72.7 60.1 Content area: Complications of CKD > 6th grade Reading level 6th grade Characteristics General Minority or Ethnic Target population Are you at risk for CKD Sodium: risk factors for CKD Iron and kidney disease Complications of CKD Living well with CKD Living well with CKD Staying active with CKD Nutrition and CKD Diabetes and CKD Anemia and CKD Working title Basicsof CKD About CKD Anemia Kidney School Kidney School Kidney School NKDEP Source AAKPNKF NKF AKFNKF NKF NKF AKFNKF

			Characteristics	istics			Domain ratings (%)			γα	
	Working title	Targ	get population	Readin	Reading level	Median contract	E TOTAL CONTRACTOR OF THE PARTY	Vicinola	1 02:01	Domain Doting	
		General	Minority or Ethnic 6th grade >6th grade	6th grade	> 6th grade	Message content	ressage content 1 ext appearance visuais Layout	v isuais	Layout	(%)	Symbol
	CKD and medications	*		*		<i>L</i> .69	2.99	2.99	83.3	71.6	•
_											

Abbreviations: NKDEP=National Kidney Disease Education Program; AKF=American Kidney Fund; NKF=National Kidney Foundation; AAKP: American Association of Kidney Patients;

NOTE: maximum rating = 100. Symbols represent Superior, Adequate or Inadequate ratings.