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Health care increasingly requires complicated self-care regimens that demand patients and family caregivers learn about unfamiliar topics and practices to support their recovery. Due to the prevalence of low health literacy, patient education materials must comply with health literacy standards so that all patients understand how to take care of themselves. This content analysis examines the quality and consistency of patient education materials used at a large academic medical center to inform self-care of burns, tracheostomy, and peripherally-inserted central catheters. The Patient Education Material Assessment Tool (PEMAT) was used to evaluate thirteen patient education materials from inpatient, outpatient, and home health settings. PEMAT scores were associated with the presence of visual aids and document source. Consistency of materials was greatest among documents describing self-care for burns. Study methods employed may be used as a foundation for assessment of additional patient education materials.

Headings

Patient education

Self-care

Content analysis - communication

Health literacy

Patient Education Material Assessment Tool (PEMAT)

Library schools - Theses - University of North Carolina at Chapel Hill

A CONTENT ANALYSIS OF PATIENT EDUCATION MATERIALS ACROSS THE CONTINUUM OF CARE: CONSISTENCY AND ACCESSIBILITY

by Erica R. Brody

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Approved by

Mary Grace Flaherty

Introduction

Tina is being discharged home from the hospital after five days of treatment for a staph infection. She is pleased to return home and hopes to finish the semester with her English literature students at the local college. However, she is nervous about giving herself antibiotic medications intravenously. The nurse at the hospital spent about twenty minutes reviewing the procedure with her today and gave her some written materials about how to do it, and the home health nurse gave her some more educational pamphlets when she visited. When Tina reviews the papers from the hospital and home health, they seem overwhelming, so Tina is afraid that she might do something wrong and end up sick again, or even worse, back in the hospital.

Health care has changed significantly over the past 30 years, characterized in part by shorter hospital stays (Avalere Health, 2015; Bueno et al., 2010; Kaboli et al., 2012; Weiss Aj, 2014). Spending less time in the hospital has upsides and downsides. While patients might welcome the opportunity to escape the frenetic and noisy environment of the hospital and return back to their "normal" lives, leaving the hospital before one is fully healed can be scary (Bhole, Burton, & Chapel, 2008). Increasingly, patients are being tasked with complicated self-care regimens at home, such as intravenous or parenteral medication and care for substantial wounds. Patients and family caregivers are required to learn about unfamiliar topics and practices fairly quickly in order to support their recovery. Poor or incomplete compliance with these care regimens can have significant negative consequences, such as delays in recovery, infection, or readmission to the hospital (Ball, 2013; Cox & Westbrook, 2005; Pieper et al., 2007).

When patients stayed in the hospital receiving all care from doctors, nurses, and therapists until they were fully recovered, health care quality was largely determined by provider knowledge about a patient's condition and ability to deliver appropriate care. As patients take on responsibility for their well-being, health care providers have had to take on the role of patient educators. Patient education has become an important element of quality of care (Office of Disease Prevention and Health Promotion at U.S. Department of Health and Human Services, 2010). For example, the 2016 plans for The National Quality Strategy at the Centers for Medicare and Medicaid states that a condition necessary to meet its stated goals is "Consumers have increased access to understandable health Information" (Agency for Healthcare Research and Quality, 2016, p. 12).

Although patient education is critical to recovery from illness, delivering these instructions effectively can be challenging due to patient characteristics, as well as the nature of health care delivery. Overall, health literacy in the U.S. is low, with only 12% of American adults exhibiting proficiency. Proficiency is defined as the ability to "obtain, process and understand the basic health information and services they need to make appropriate health decisions" (Koh & Rudd, 2015).

In stressful situations (like coping with illness), even highly educated people may have difficulty learning new information (Fredericks, Sidani, & Shugurensky, 2008; Lapum, Angus, Peter, & Watt-Watson, 2011; Stephenson, 2006). People have different learning styles; some learn best from hearing new information, while others prefer to get hands-on practice, and still others like to read unfamiliar information (Ball, 2013; Giuse, Koonce, Storrow, Kusnoor, & Ye, 2012; Inott & Kennedy, 2011). In addition, patients may have difficulty adapting educational information received in the hospital to the reality of their home setting (Cain, Neuwirth, Bellows, Zuber, & Green, 2012).

In the hospital, doctors and nurses often have limited time to spend educating patients (Block, Morgan-Gouveia, Levine, & Cayea, 2014; Frank-Bader, Beltran, & Dojlidko, 2011; Inott & Kennedy, 2011). Family caregivers who help patients recover at home might not be included in patient education sessions. Therefore, it is important that patients receive written educational materials that they can review at their convenience (e.g. when they are ready to absorb new information, or at the point in time when they need to conduct self-care activities). Health literacy standards for patient education materials have been developed to ensure that these materials are helpful to patients. For example, the Agency for Research and Quality (AHRQ) has developed a set of health literacy standards addressing understandability and actionability, i.e., patients get checklists to do the tasks required or examples of how to perform mathematical calculations (S. J. W. Shoemaker, Michael S.; Brach, C., 2013).

Patients receive educational materials from a variety of health care settings, including inpatient units, outpatient clinics, and home health care providers. The patient education materials provided in these different settings might not be the same. For example, they may provide information about different activities or subsets of practices or use different words to describe the same phenomenon. This author believes that inconsistencies in patient education materials could cause confusion among patients and result in poorly administered home care and potentially, adverse events (e.g., infection), delays in recovery, or hospital readmission.

There are ways to help ensure that patients receive consistent information about self-care interventions. In particular, health care systems that are comprised of providers from the full continuum of health care settings have the opportunity to standardize patient education materials across the organization. This study involves a large academic medical center (referred to as the system) that offers a full continuum of care from inpatient to outpatient to home health care services. The system has deployed a common electronic health record system, Epic. In an effort to comply with meaningful use requirements of Health Information Technology for Economic and Clinical Health Act¹, the system adopted a set of patient education materials from an approved national vendor (referred to as the vendor). These materials are distributed through the Epic system.

Anecdotal information suggests that the vendor's patient education materials are not used consistently by all of the system's providers. As an example, outpatient providers may be using "home grown" materials.

This project examines the quality of patient education materials used at the system to inform self-care of burns, tracheostomy, and peripherally-inserted central catheters (PICC). The content analysis evaluates the understandability, actionability, and consistency of materials across inpatient, outpatient, and home health settings. Results

¹ Title XIII of the American Recovery and Reinvestment Act (ARRA), called the Health Information Technology for Economic and Clinical Health Act, requires that providers use clinically relevant information from a Certified EHR Technology (CEHRT), like Epic, to identify patient-specific education resources and provide those resources to the patient.

will be used to determine if actions are needed to initiate any improvements in patient education materials used at the system.

Literature Review

Effective patient education is more important than ever as hospital stays get shorter, and patients are expected to take on a larger role in managing their health care (Avalere Health, 2015; Bueno et al., 2010; Weiss and Elixhauser, 2014). In particular, patients are asked to participate in complicated self-care regimens at home, such as giving themselves medication intravenously or caring for serious wounds (Ball, 2013; Polzien, 2006). Failing to conduct these activities properly can have significant negative consequences, such as delays in recovery, infection, or readmission to the hospital (Chen et al., 2013; Gorski, 2010; McCaskey, 2009).

Numerous factors influence a patient's ability to conduct medically technical selfcare activities correctly, including social support, home environment, culture, and patient knowledge and engagement (Arbaje et al., 2008; Barnett, Hsu, & McWilliams, 2015). Many of these factors are outside the influence of health care providers, yet health care providers can impact self-care success by educating patients about the tasks they need to perform.

In the US, only about 12% of the population is health literate (Koh & Rudd, 2015). While increasing health literacy across the population is an important goal, patient education interventions need to accommodate patients of all literacy levels by adhering to best practices that effectively engage the patient and communicate information to patients in ways they can understand. There is evidence that patient education is not always provided according to best practice, if at all (Block et al., 2014). Therefore, written

patient education materials that patients can review as many times as needed at their convenience are critical to the success of patient self-care efforts. Research about adult learning principles and effective communication with low-literacy populations has informed the development of best practice guidelines for the development of written patient education materials.

Health Literacy in the U.S.

The 2003 National Assessment of Adult Literacy provides the most recent statistics describing health literacy in the U.S. The study uses the following definition of health literacy obtained from the U.S. Department of Health and Human Services and the Institute of Medicine, "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Kutner, Greenberg, Jin, & Paulsen, 2006, p. 3). Rather than obtaining self-reports of health literacy, this large study of more than 19,000 Americans examined responses to 28 questions using written (both prose and numeric) information provided. This study found the following:

- Twelve percent of Americans have **proficient health literacy** (skills necessary to perform more complex and challenging literacy activities)
- Fifty-three percent of Americans have **intermediate health literacy** (skills necessary to perform moderately challenging literacy activities)
- Twenty-two percent of Americans have **basic health literacy** (skills necessary to perform simple and everyday literacy activities)
- Fourteen percent to Americans have **below basic health literacy** (no more than the most simple and concrete literacy skills)

In stressful situations (like coping with an illness), even highly educated people may have difficulty learning new information (Fredericks et al., 2008; Lapum et al., 2011; Stephenson, 2006). Further, during hospitalization patients may be taking drugs that temporarily interfere with cognition and compromise understanding of new information.

Since U.S. health literacy rates are low and anxiety or medication may interfere with patient cognition, most guidelines recommend that patient education materials be written at a 5th grade reading level, and at no higher than a 6th-8th grade reading level (DeWalt, 2010; Doak, Doak, & Root, 1996). In addition, several sets of guidelines and best practices have been developed to support the development of high quality patient education materials.

Best practices: Patient education

People have different learning styles; some learn best from hearing new information, while others prefer to get hands-on practice, and still others like to read unfamiliar information (Ball, 2013; Brega et al., 2015; Giuse et al., 2012; Inott & Kennedy, 2011). Generally, people learn new information best when they have the opportunity to review it on more than one occasion. In written materials, pictures help patients to focus on, remember, understand, and comply with health information (Houts, Doak, Doak, & Loscalzo, 2006; Zeng-Treitler, Kim, & Hunter, 2008). Research also shows that patients who receive only one or two pieces of advice from their provider are more likely to be able to remember this information than those who hear three or more recommendations (Selic, Svab, Repolusk, & Gucek, 2011). A recent systematic literature review provides evidence that multimedia education is at least as effective as written material and one-on-one education with a health care provider. In addition, multimedia education is more effective when paired with another source of information, either written or in-person education (Ciciriello et al., 2016).

Another effective strategy is the Teach Back method, whereby patients tell or show their provider the information they understood from the medical advice they received during the health care visit. Patients who are engaged in the Teach Back process are significantly more likely to remember that information as they leave the health care facility (Bravo et al., 2010; Peter et al., 2015). Further, patients prefer participating in the Teach Back method, compared with receiving didactic instructions from providers (Kemp, Floyd, McCord-Duncan, & Lang, 2008).

In addition, during the education process, providers should acknowledge that conducting invasive self-care tasks may bring up emotions such as fear among patients. For example, caregivers who assist with home infusion report anxiety about hurting their loved ones when providing care (Cox & Westbrook, 2005).

Evidence that patient education during care transitions is not ideal

There is a strong evidence base for best practices in patient education. However, provider compliance with these guidelines is variable and, in some cases, patients receive no education.

Kalisch, McLaughlin, and Dabney (2012) interviewed 38 hospital patients to assess which elements of nursing care they received. Patient education was one of several nursing interventions that was frequently missed. In another study, 76 patients getting ready for discharge from a large urban acute care hospital were interviewed about their knowledge and concerns for wound care before going home. Two of every three patients reported that they received no education about wound care before discharge (Pieper et al., 2007). Similarly, Mudge, Shakhovskoy, and Karrasch (2013) found that 67% of medical records of 209 hospitalizations reviewed contained no documentation of patient education (outside of pharmacist review of medications).

Block et al. (2014) asked medical students about their experiences and thoughts regarding the hospital discharge process. Seventy-eight medical students documented their "reflections" about the "barriers to safe discharges and solutions to improve the discharge process" (p. 1148). One of the most frequently cited barriers to safe discharges was lack of patient education. Students noted that providers had insufficient time to educate patients, and they observed that the Teach Back method was not used consistently with patients.

Importance of written patient education materials

Since the use of best practices in patient education is variable, it is important that patients receive written educational materials that they can review at their convenience, when they are ready to absorb new information or at the point in time when they need to conduct self-care activities.

Several systematic reviews of the literature have examined the benefits of written patient education. Johnson, Sandford, and Tyndall (2003) found that parents obtained a greater understanding of the care they needed to provide to their children at home after discharge from the hospital when they received written materials and verbal instructions compared to receiving only verbal education based on two studies of approximately 300 patients. Another Cochrane review of 25 randomized controlled trials involving almost 5,000 patients examined the outcomes associated with providing written information about medications. Twelve of these studies assessed patient knowledge of medications when given written information compared with providing no information. Half of these studies found increased patient knowledge with written information, three studies yielded a mix of significant and non-significant results, and the remaining three studies found no significant difference (Nicolson, Knapp, Raynor, & Spoor, 2009). This systematic analysis shows that written materials have at least moderate benefit and, at a minimum, do no harm.

Written information about disease and treatment options is highly valued among patients. Focus groups with 40 cancer patients revealed that their education binder "provided them with a way to organize their personal information and begin to plan how they would move forward. Information could be read at the patient's own pace, and read by family members who would, in turn, assist the patient in sorting the personally meaningful details and reinforcing how to obtain other needed information" (Marbach & Griffie, 2011, p. 338). Similarly, a survey of urological surgery patients (n=99) one week post-discharge found that patients receiving a booklet of discharge instructions reported having a more positive health care experience and had fewer concerns going home than those who did not receive the booklet (Fagermoen & Hamilton, 2006). Family caregivers of patients on home infusion treatment also reported that printed education materials are valuable, "the provision of simple, yet comprehensive, written instructions that are congruent with the procedures taught creates a secure structure for ongoing guidance and reinforcement to the caregiver" (Cox & Westbrook, 2005, p. 106).

Best practices for written patient education materials

The Agency for Healthcare Research and Quality (AHRQ) is the lead federal agency responsible for improving health care quality and safety in the US. AHRQ sponsored the development of the Health Literacy Universal Precautions Toolkit to help primary care providers adopt practices to improve communications with patients and help them navigate the health care system. This toolkit provides evidence-based guidance to practices for improving health communication and serves as the standard of best practice for this study.

Since health literacy is often not a trait that can be directly observed, the toolkit provides "universal precautions," i.e. strategies to help everyone (DeWalt, 2010). Within this toolkit, Tool 11 provides guidance on patient education materials, including resources to accomplish the following:

- "Train a staff member to evaluate the quality of materials you give to patients.
- Assess whether patient materials are easy to read and understand.

Choose or make materials that are easy to understand" (DeWalt, 2010).
 Toward this end, Tool 11 includes website links to several "Understandability
 Assessments," including the Patient Education Material Assessment Tool (PEMAT)
 developed by AHRQ, the Suitability Assessment of Materials (SAM) (Doak et al., 1996),

and the Center for Disease Control and Prevention (CDC) Clear Communication Index discussed in turn below.

The PEMAT is a set of health literacy standards addressing understandability and actionability of written and audiovisual materials (S. J. W. Shoemaker, Michael S.; Brach, C., 2013). The authors of the tool define understandability and actionability as follows:

Patient education materials are understandable when consumers of diverse backgrounds and varying levels of health literacy can process and explain key messages. Patient education materials are actionable when consumers of diverse backgrounds and varying levels of health literacy can identify what they can do based on the information presented (S. J. Shoemaker, Wolf, & Brach, 2014, p. 396).

The PEMAT items reflect a wide range of best practices for written materials. The purpose of the material should be clear. Materials should be comprised of plain language written in an active voice. Numbers are easy to understand, and users are not prompted to conduct calculations. Formatting (e.g., bullets), headings, and visual aids direct users to "key points" and help promote understanding of the information provided. Materials should also break down tasks into manageable steps to help users take action (S. J. W. Shoemaker, Michael S.; Brach, C., 2013).

One of the most-cited resources for best practice in communicating health information to people with low literacy skills is the book, *Teaching Patients with Low Literacy Skills* (Doak et al., 1996). The authors created the Suitability Assessment of Materials (SAM) that reflects their understanding of best practice in health communication. The tool is comprised of 17 items that address the organization, writing style, appearance, and appeal of a patient education document (Doak et al., 1996).

The third resource for written communication guidelines in the AHRQ toolkit is the CDC's Clear Communication Index. This tool supports the development of public health communications materials and focuses on the use of plain language. Although the tool was developed to help CDC personnel produce materials that comply with the Plain Writing Act of 2010, anyone can use the index to guide development or evaluation of public communications about health. The 20 items in the index address the following elements of health communication documents:

- 1. Main Message and Call to Action,
- 2. Language,
- 3. Information Design,
- 4. State of the Science,
- 5. Behavioral Recommendations,
- 6. Numbers, and
- 7. Risk (Centers for Disease Control and Prevention, 2015).

The elements of these three assessment tools define best practice for patient education materials. As shown in the **Table 1** below, there is significant overlap among the elements of each tool. Extracting the common items between the instruments yields the following list of best practices for written educational materials:

- Materials should have a clear purpose, which includes one or two key messages
- Materials should not include information out of the main purpose that may detract

from key messages

- Material is presented in a logical order
- A summary of key points is presented
- Visual cues (e.g., arrows, boxes, bullets, shading) draw attention to key points
- Visual aids with clear captions or titles are used to make content more easily understood, while not distracting from the key messages
- The material describes at least one action the user can take, which is broken down into manageable steps
- The material uses common, everyday language and active voice
- Material is chunked or displayed in short sections separated by meaningful headings
- Numbers are clear and easy to understand
- Readers are not expected to conduct calculations.

| РЕМАТ | CDC Clear Communication Index | SAM |
|--|--|--|
| The material makes its purpose completely evident | Is the main message at the top, beginning, or front of the material? | Purpose is evident |
| The material does not include information or content that distracts from its purpose | | Content – scope is limited |
| The material presents information in a logical sequence | | Layout factors, i.e. easy for the patient to predict flow of information |
| The material provides a summary | | Summary or review included |
| | Does the material contain one message statement? | Scope is limited |

Table 1. Best practices for patient education materials from the PEMAT, SAM,and CDC's Clear Communication Index

| РЕМАТ | CDC Clear Communication | SAM |
|--------------------------------------|---|-------------------------|
| | | X 7' 1 ' 1 ' |
| The material uses visual cues | Is the main message emphasized | Visual cuing devices |
| (e.g., arrows, boxes, bullets, bold, | with visual cues? | (shading, boxes, |
| larger font, highlighting) to draw | | arrows) used to direct |
| attention to key points | | attention to specific |
| | | points or key content |
| The material uses visual aids | Does the material contain at least | Relevance of |
| whenever they could make | one visual that conveys or | illustrations |
| content more easily understood | supports the main message? | |
| (e.g., illustration of healthy | | |
| portion size) | | |
| The material's visual aids | | Type of graphics |
| reinforce rather than distract from | | (promote realism |
| content | | without including |
| | | distracting details |
| The material's visual aids have | | Captions used for |
| clear titles or captions | | graphics |
| The material uses illustrations and | | Type of graphics |
| photographs that are clear and | | (promote realism |
| uncluttered | | without including |
| | | distracting details |
| The material clearly identifies at | Does the material include one or | Content about |
| least one action the user can take | more calls to action for the primary audience | behaviors |
| The material uses the active voice | Do both the main message and | Writing style, active |
| | the call to action use the active | voice |
| | voice? | |
| The material uses common, | Does the material <u>always</u> use | Vocabulary uses |
| everyday language | words the primary audience | common words |
| | understands? | |
| The material's sections have | | Learning aids via "road |
| informative headings | | signs" i.e., headings |

| The material uses visual cues | Does the material use bulleted or | Visual cuing devices |
|--------------------------------------|-----------------------------------|------------------------|
| (e.g., arrows, boxes, bullets, bold, | numbered lists? | (shading, boxes, |
| larger font, highlighting) to draw | | arrows) used to direct |
| attention to key points | | attention to specific |
| | | points or key content |
| The material breaks or "chunks" | Is the material organized in | Subheads ("chunking") |
| information in short sections | chunks with headings? | used |
| The material breaks down any | Does the behavioral | |
| action into manageable, explicit | recommendation(s) include | |
| steps | specific directions about how to | |
| | perform the behavior? | |

| The material uses visual cues | Does the material use bulleted or | Visual cuing devices |
|--------------------------------------|---|-------------------------|
| (e.g., arrows, boxes, bullets, bold, | numbered lists? | (shading, boxes, |
| larger font, highlighting) to draw | | arrows) used to direct |
| attention to key points | | attention to specific |
| | | points or key content |
| The material provides a tangible | | Material encourages |
| tool (e.g., menu planners, | | reader interaction with |
| checklists) whenever it could help | | the information |
| the user take action | | |
| Numbers appearing in the | Does the material <u>always</u> present | |
| material are clear and easy to | numbers the primary audience | |
| understand | uses? (i.e., limit use of | |
| | percentages, decimals, fractions) | |
| | Does the material always explain | |
| | what the numbers mean? | |
| The material does not expect the | Does the audience have to | |
| user to perform calculations | conduct mathematical | |
| | calculations? (this is not | |
| | desirable) | |
| The material explains how to use | | List, tables, etc. |
| the charts, graphs, tables, or | | explained |
| diagrams to take actions | | |
| | | |

The PEMAT also includes the following criteria:

- The material addresses the user directly when describing actions
- Medical terms are used only to familiarize audience with terms. When used, medical terms are defined.
- The material uses simple tables with short and clear row and column headings
- The material uses visual aids whenever they could make it easier to act on

instructions

The SAM also includes:

- Reading level
- Cover graphic shows purpose
- Typography (type size and fonts are easy to read)

- Behaviors are modeled and specific
- Motivation self-efficacy
- Cultural appropriateness match in logic, language, experience
- Cultural appropriateness cultural image and examples
- Context is given first

The CDC Clear Communication index also asks:

- Is the most important information the primary audience needs summarized in the first paragraph or section?
- Does the material explain what authoritative sources, such as subject matter experts and agency spokespersons, know and don't know about the topic?
- Does the material include one or more behavioral recommendations for the primary audience?
- Does the material explain why the behavioral recommendation(s) is important to the primary audience?
- Does the material explain the nature of the risk?
- Does the material address both the risks and benefits of the recommended behaviors?
- If the material uses numeric probability to describe risk, is the probability also explained with words or a visual?

Consistency of patient education

Consistency is highly valued in healthcare. John Wennberg's *Dartmouth Atlas of Health Care* (Wennberg, 1996) showed significant variation in the practice of healthcare throughout the country. In an ideal world, we would have evidence-based interventions to address all health conditions, and everyone with a particular health condition would receive this scientifically proven treatment. However, there are a lot of medical situations that are not informed by empirical evidence, e.g., the conditions under which a patient with congestive heart failure should be hospitalized (Wennberg, 2010). As a result, there is significant unnecessary and undesirable geographic variation in the utilization and cost of health care around the country (Wennberg, 2010). While there is a significant body of research about the absence of consistency in health care utilization and costs, consistency of patient education across care settings has received little attention.

Patients with serious health conditions typically receive care from multiple providers in inpatient and outpatient settings, as well as from home health care providers. Each of these providers may have their own patient education documents to describe a single self-care activity. The documents may provide information about different activities or subsets of practices or use different words to describe the same phenomenon. Such inconsistencies in patient education materials may confuse patients, result in poorly administered self-care and potentially, adverse events (e.g., infection), delays in recovery, or hospital readmission. A survey of approximately 100 cardiac patients receiving care from different providers within the same hospital provides an illustrative example. In the hospital waiting areas, these patients found a variety of patient education brochures about the same topics and reported that this caused confusion (Gershenson, Quon, Somerville, & Cohn, 1999). Similarly, interviews with caregivers assisting with home infusion treatment recommended providing a "standardized instruction sheet and checklist for skill learning" to patients for this complicated self-care regimen (Cox & Westbrook, 2005, p. 106).

Davies, Papa, Ischia, Bolton, and Lawrentschuk (2015) examined consistency of written patient education materials for post – urological surgery from 9 hospitals in Australia and online information available from all urologists in Australia. The authors looked at the following four elements of each educational document: "(i) specific post-operative instructions and timing; (ii) restrictions on normal activities (particularly return to driving, work, exercise and sex); (iii) expected symptoms and duration; and (iv) when to seek medical attention" (Davies et al., 2015, p. 942). This review revealed substantial variation among more than 200 documents, particularly regarding expected symptom duration and recommendations for when to resume normal activities.

Despite the existence of evidence-based guidelines for patient education materials, studies have shown that compliance with these standards is variable (Brega et al., 2015). Health care providers need to assess their patient education materials to identify opportunities for improvement. This study examines patient education materials used at the system for compliance with best practice for understandability, actionability, and consistency across inpatient, outpatient, and home health care settings. Data collected will be used to determine the need for improvement of these materials.

Methods

A content analysis was conducted to assess the quality and consistency of patient education materials used at the system. Content analysis can be used to examine latent or manifest content of materials. Latent content is that which the analyst infers from language present using inductive reasoning. In contrast, analysis of manifest content focuses on the nature of the actual words used in the documents under study (Graneheim & Lundman, 2004; Spurgin & Wildemuth, 2009). This study examined the manifest content of patient education materials, i.e., the content and formatting of the documents. *Sampling Strategy*

Materials examined include education materials about self-care activities for patients with burns, a tracheostomy, or a peripherally inserted central catheter (PICC line). A two-pronged sampling strategy was used to obtain the sample of education materials for analysis. Health conditions were selected using a purposive sampling strategy, whereas a convenience sample was used to select the healthcare providers from which the education materials were obtained as discussed below.

Sample of health conditions

The study was conducted to support quality improvement of patient education materials at the system, a practical real-world problem. Purposive sampling was used to obtain data that is of pragmatic importance to the primary study audience, the health care system (Emmel, 2016). The health conditions chosen were expected to produce "information-rich cases" for study in depth (Patton, 2002, p. 46). Specifically, these conditions are treated in multiple health care settings (i.e., inpatient, outpatient, and home health) and require self-care activities that are complicated and typically require new knowledge among laypersons.

Sample of health care providers

The sample was taken from all hospitals and more than 100 outpatient practices within the system. Inpatient education was sought from one hospital within the system.

Outpatient materials were requested from the system's burn center; ear, nose and throat clinic; and the vascular interventional radiology clinic associated with this hospital. This convenience sample of inpatient and outpatient settings was selected based on the author's relationships with a home infusion nurse and a member of the system's Performance Management team. These individuals had existing relationships with personnel at the selected locations, which facilitated the process of obtaining access to patient education materials in use. There is only one home health care provider in the system, therefore no sampling strategy was needed for this care setting.

Data collection

An attempt was made to access printed versions of patient education materials for analysis. Efforts were made to obtain all patient education materials used by each of the selected health care settings to address self-care practices for burns, PICC lines, and tracheostomies.

Analysis Framework

The study investigated the following:

- 1. the degree to which patient education materials comply with health literacy standards and
- 2. the consistency of materials across patient care settings.

The Patient Education Materials Assessment Tool (PEMAT) was used to assess compliance with health literacy standards. As discussed in the literature review, the PEMAT was developed under the leadership of the Agency for Healthcare Research and Quality to support the assessment of patient education materials for understandability and actionability (S. J. Shoemaker, 2013). "Patient education materials are understand- able when consumers of diverse backgrounds and varying levels of health literacy can process and explain key messages. Actionability: Patient education materials are actionable when consumers of diverse backgrounds and varying levels of health literacy can identify what they can do based on the information presented" (S. J. Shoemaker et al., 2014, p. 396).

The PEMAT was selected for its strong psychometric properties and ease of use. Both the understandablity and actionability scales were found to have strong internal consistency. The tool provides reliable results with untrained raters. Unlike other assessment tools, the PEMAT measures the degree to which educational materials promote patient action. In addition, the tool's construct validity was tested with actual consumers (Shoemaker et al., 2014). The PEMAT instrument is provided in the Appendix.

As discussed in Chapter 2, consistency is a strong value in health care. However, there is currently very little research on the consistency of patient education materials. Consequently, the following data elements were abstracted from each of the education materials in order to evaluate their consistency across care settings:

- Key medical terms used throughout the document used to name health conditions, self-care practices, and equipment – e.g., self-infusion, PICC line
- Content of the instructions provided, i.e., the "aboutness" of each document
- Name and phone number for the patient or caregiver to call when problem or concern arises
- Signs or symptoms that require consultation with the doctor or home health nurse

The focus of this content analysis was the language and formatting of patient education documents. While also important, the quality of information and cultural sensitivity of the materials was outside the purview of this study. In addition, reading level was not assessed, because patient education materials were not obtained in electronic format.

Data were abstracted from each patient education document and recorded into a form in a Libre Office database. To help ensure consistency in data coding, the first 20% of materials reviewed were re-examined at the end of data collection to recreate PEMAT scores and data elements related to consistency.

Analysis

Quantitative analysis of PEMAT data was conducted using Microsoft Excel. Specifically, PEMAT understandability and actionability scores for each patient education material reviewed were created using count and sum functions and a simple mathematical formula, as described in the PEMAT instructions found in the Appendix. Consistency of information covered by the documents was assessed qualitatively using data formatted into reports using the database in Libre Office.

Results

Thirteen patient education materials were obtained between April and September 2016. The distribution of materials by health condition and care setting is provided in **Table 2.** The majority of materials were from the inpatient setting. All documents about PICC lines used in the outpatient setting were also used in the inpatient setting.

The patient education materials came from three different sources, system staff, the vendor, and the After Visit Summary generated by the care team. The eight materials created by system staff were developed and standardized using a group process with oversight. In contrast, the two After Visit Summaries were written by a single provider in the absence of any review with no measures to ensure consistency across providers or patients. Three items were supplied by the vendor of patient education materials. **Table 3** provides a brief description of each item obtained.

| | Inpatient | Outpatient | Home Health |
|--------------|---|---|---|
| Burn | Caring for your Burn at Home : Bathing & Wound Care Pain & Itching 5 East Burn Care Discharge information NC Jaycee Burn Center Adult discharge information Discharge instructions from inpatient After Visit | Discharge instructions from outpatient After Visit Summary | |
| Tracheostomy | Summary A Second Breath: Home Care for Patients with Tracheostomy Your Tracheostomy: Care Instructions (vendor) | | • How to use your portable suction machine |
| PICC | PICC line care booklet PICC: Care Instructions (vendor) PICC brochure Learning about a Central Venous Catheter (vendor) | PICC line care booklet PICC: Care Instructions (vendor) PICC brochure Identical to items distributed in inpatient setting | |

 Table 2. Distribution of Patient Education Materials by Health Condition

 and Care Setting

| Title | Source | Pages | Graphics |
|--|------------------------|---------------------|----------|
| Caring for Your Burn at Home: Bathing & Wound Care | system staff | 4 | 0 |
| Pain & Itching | system staff | 2 | 0 |
| 5 East Burn Care Discharge information | system staff | 2 | 0 |
| NC Jaycee Burn Center Adult discharge information | system staff | 2 | 0 |
| Discharge instructions from inpatient | after visit summary | 2 | 0 |
| Discharge instructions from outpatient | after visit summary | 2 | 0 |
| A Second Breath: Home Care for Patients with Tracheostomy | system staff | 18 | 19 |
| Your Tracheostomy: Care Instructions | vendor | 3 | 0 |
| How to use your portable suction machine | system staff | 3 | 0 |
| PICC line care booklet | system staff | 12 | 40 |
| PICC: Care Instructions | vendor | 2 | 0 |
| PICC brochure | system staff | 1 page (trifold) | 3 |
| Learning about a Central Venous Catheter | vendor | 3 | 1 |

Table 3. Patient Education Material Descriptions

During the data reliability assessment, which consisted of reviewing the first three materials a second time after reviewing the other ten items, discrepancies were observed in ratings of PEMAT item 12, i.e., "The material uses visual cues (e.g. arrows, boxes,

bullets, bold, larger font, highlighting) to draw attention to key points (Shoemaker, S. J. W.; Michael S.; Brach, C., 2013). During review of the first materials, more subtle visual cues generated agreement with this statement than during review of materials assessed later in the process. As a result, the detailed instructions for rating use of visual cues were reviewed and PEMAT item 12 was rescored for all the materials at the same time. *Understandability and Actionability of Patient Education Materials*

Once the dataset was finalized, PEMAT understandability and actionability scores were calculated. Overall, understandability scores ranged from 54% to 100% with an average score of 76%, and actionability scores ranged from 60% to 100% with an average score of 72%, as shown in **Figure 1**. More than a third of the materials had an understandability score of 77%, and more than half of the items had an actionability score of 60%.

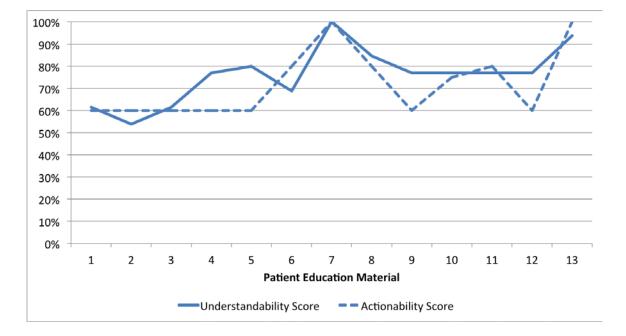


Figure 1. Understandability & Actionability Scores for each Patient Education Material Reviewed

The two patient education materials with the highest understandability and actionability scores were multi-page booklets created by system staff. Both items had a large number of visual aids and designated spaces for providers to record information specific to each patient. One of the items provides tracheostomy care instructions for patients discharged from the inpatient setting. The other high-scoring item contains instructions for PICC lines and is distributed by inpatient and outpatient staff.

Average PEMAT scores were calculated by condition, care setting, source, and the presence or absence of visual aids (**Table 4**). Materials for tracheostomy appear to have the highest scores among those examined; however the one high scoring item among the three drives this trend. Items with visual aids had higher scores than those comprised only of text. Materials created by system staff had higher scores than those from the vendor or after visit summaries. This trend is related to the fact that several of the "homegrown" materials contained visual aids, whereas none of the vendor or after visit summaries included exhibits to convey information. The small number of materials obtained precluded statistical analysis among subgroups.

| | Average | |
|---------------------|-------------------|---------------|
| Condition | Understandability | Actionability |
| burn (n=6) | 71% | 66% |
| trach (n=3) | 85% | 80% |
| PICC (n=4) | 78% | 75% |
| | Average | |
| Source | Understandability | Actionability |
| staff (n=8) | 82% | 79% |
| vendor (n=3) | 73% | 60% |
| after visit summary | | |
| (n=2) | 58% | 60% |

Table 4. Average PEMAT scores by condition, source, setting, andpresence of visual aids

| | Average | | |
|------------------------|-------------------|---------------|--|
| Setting | Understandability | Actionability | |
| inpatient (n=8) | 77% | 69% | |
| outpatient (n=1) | 54% | 60% | |
| inpatient & outpatient | | | |
| (n=3) | 77% | 80% | |
| Home health (n=1) | 85% | 80% | |
| | Average | | |
| Visual aids | Understandability | Actionability | |
| none (n=9) | 72% | 66% | |
| one or more (n=4) | 86% | 85% | |

Consistency of Patient Education Materials

An insufficient number of materials were collected from each care setting (inpatient, outpatient, and home health) to compare similarity of materials across the continuum of care. For PICC line, several materials were obtained from the inpatient and outpatient settings; however, both settings used an almost identical set of documents. Therefore, consistency of materials was assessed for each health condition studied using the following data elements:

- Content of the instructions provided, i.e., the "aboutness" of each document,
- Key medical terms used to name health conditions, self-care practices, and equipment,
- Signs or symptoms requiring consultation with the doctor or home health nurse, and
- Name and phone number for the patient or caregiver to call when problem or concern arises.

Burn care

The following six materials about burn care contained highly consistent information:

- System staff "Caring for Your Burn at Home: Bathing & Wound Care"
- System staff "Pain & Itching"
- System staff "5 East Burn Care Discharge information"
- System staff "NC Jaycee Burn Center Adult discharge information"
- After Visit Summary "Discharge instructions from inpatient setting"
- After Visit Summary "Discharge instructions from outpatient setting"

The first two documents listed addressed a single issue: bathing and wound care and pain and itching. The last four items provided information about multiple topics, such as bathing and changing dressings, attending follow-up medical appointments after discharge from the hospital, care for pain and itching, and sun protection. The materials used similar terms to describe burn care, i.e. purulent discharge, infection, dressings, gauze, ace wraps, and Xeroform.

Five materials provided a list of symptoms that merit contact with a health care provider. Four items mentioned presence of fever; redness, pus, or foul smell from burn; and increased pain. Two materials mentioned excessive bleeding at wound sites,

uncontrolled nausea or vomiting, and new or concerning symptoms. The document about pain and itching encourages patients to contact the Burn Team if they experience a lot of itching.

Four items include identical contact information for the burn surgery clinic when problematic symptoms are observed. Three of these items also contain the phone number the burn inpatient unit, while the other item included a different second phone number.

Tracheostomy Care

The following three patient education materials about tracheostomy do not contain any inconsistencies:

- Vendor "Your Tracheostomy: Care Instructions" (referred to as Your Tracheostomy)
- System staff "A Second Breath: Home Care for Patients with Tracheostomy" (referred to as A Second Breath)
- System staff "How to use your portable suction machine"

One of the materials explains how to use and care for a portable suction machine, while the other two documents focus on caring for the tracheostomy. These two documents use similar terminology throughout. Overall, one of the documents, Your Tracheostomy provides a subset of the information contained in A Second Breath.

Both of these documents include the following information about tracheostomy care:

- description of a tracheostomy,
- care for the stoma and inner cannula,

- suctioning, and
- symptoms requiring medical attention.

A Second Breath also provides information about the following issues:

- description of an outer cannula,
- indicators of sputum changes,
- changing tracheostomy ties,
- clearing the airway,
- tracheostomy's effects on one's normal routines,
- the need to be on the power company's Medical Alert/Medical Priority List,
- a supply list, and
- a schedule for various tasks associated with tracheostomy care.

In addition, A Second Breath describes two types of inner cannulas, one that is reusable and one that is disposable. In contrast, Your Tracheostomy mentions only the inner cannula without indicating the presence of two types.

The two documents both recommend calling a doctor in the presence of the following symptoms:

- difficulty breathing,
- signs of infection, and
- the tracheostomy falls out and cannot be re-inserted.

A Second Breath provides greater detail about each of these potential problems than Your Tracheostomy. For example, A Second Breath lists symptoms separately for two different types of infection: respiratory and stoma infection. Your Tracheostomy indicates that you should call for help if "You have severe trouble breathing, and coughing or suctioning does not help." In contrast, A Second Breath lists the following signs of respiratory distress:

- increased rate of breathing or shortness of breath,
- very deep or very shallow breaths,
- noisy breathing (wheezing or gurgling),
- increased pulse rate,
- restlessness or agitation,
- changes in skin color (blue or unusually pale),
- sweating, and
- change in level of alertness (increasingly tired and less active).

The two materials use different approaches for providing contact information for the health care provider when problems arise. Your Tracheostomy indicates that one should call 911 or your doctor (with no phone number provided). In contrast, Second Breath allows the booklet to be customized for each patient with spaces to write in doctor name, nurse name, clinic telephone number, and home-health number on front page of booklet. In addition, A Second Breath provides the specific phone number for the hospital operator on its inside cover. In contrast, the document about how to care for the suction machine did not contain information about symptoms to trigger contact with a health care provider; however, the phone number for the systems homecare service was printed in the footer of each page.

PICC Lines

Four patient education materials about PICC lines were obtained, two from the vendor and two created by system staff. The materials are titled as follows:

- Vendor "Learning about a Central Venous Catheter" (referred to as CVC),
- Vendor "Peripherally Inserted Central Catheter (PICC): Care Instructions" (referred to as PICC care instructions)
- System staff "PICC Brochure for Patients and Families" (referred to as PICC brochure)
- System staff "PICC Line Care" (referred to as PICC booklet)

Generally, these materials use similar terms, such as PICC line, line, and catheter. The PICC brochure is the only item that includes the following medical terms: Lidocaine, total parenteral nutrition, and hard sticks.

All of the items describe a PICC line and its purpose, i.e., to give patients medicine, nutrients, blood products, or fluid intravenously. CVC describes the central venous catheters more generally and notes that a PICC line is a type of central venous catheter. In addition, all four materials provide general tips for caring for the PICC line, e.g., wash hands before touching, wear loose clothes, and keep the area near the PICC line dry.

With the exception of the PICC booklet, all of the materials describe the process of inserting a PICC line. The PICC care instructions and CVC provide a brief description of this procedure, whereas the PICC brochure provides detailed information. The PICC brochure is targeted at patients whose PICC lines will be removed before they leave the hospital, while the other three documents mention at least some information about caring for the PICC line at home. Two of the documents (PICC brochure and CVC) describe risks associated with PICC lines. Both documents note the possibility of bleeding, infection, or blockages in the catheter. The CVC also mentions the risks of pain, a collapsed lung, and shifting of the catheter.

PICC Line Care is the only patient education material that contains comprehensive instructions for a patient to care for the PICC Line at home, including hand washing, flushing a PICC line, changing the cap, changing the dressing, use of central line gloves, and a list of supplies required for care.

The PICC brochure and the PICC care instructions contain lists of symptoms that require medical attention, as shown in Table 5. Overall, the brochures note similar signs, and some of the differences seem to be due to use of terms rather than actual differences in the actual information. For example, PICC Line Care says "PICC line rips, tears, or breaks," whereas the PICC Care Instructions includes "Catheter is leaking, cracked, or clogged."

| | PICC Line | PICC Care |
|---|-----------|--------------|
| | Care | Instructions |
| PICC line comes out or is out of place | X | X |
| PICC line rips, tears, or breaks | X | |
| Cannot flush PICC line | X | X |
| Air gets into the PICC line | X | |
| Signs of PICC line infection | X | |
| • Fever | X | X |
| • Draining, oozing or bleeding from the exit site of the PICC | X | X |
| Shaking or chills | X | |
| Redness or pain around the PICC | X | X |
| Swelling around the PICC line | X | X |
| • Swelling in the face, neck, or arm | X | X |
| • Pain in arm or shoulder while | X | X |
| flushing the PICC | | |
| Red streaks leading from the area | | Х |
| Trouble breathing, breathing very fast, or | Х | X |
| feel like heart is beating very fast | | |
| Chest pain | X | Х |
| Pass out | | X |
| Cough up blood | | Х |
| Signs of blood clot (e.g. bulging veins near | | Х |
| catheter) | | |
| Fast or uneven pulse | | X |
| Cather is leaking, cracked, or clogged | | X |

Table 5. Signs and Symptoms that require medical attention

The PICC Care Instructions direct patients to call 911 or "your doctor," without providing a phone number for the health system. In contrast, PICC line care includes 911, the main number for the health system, and a place on the cover of the booklet for a provider to write in a number to call if there are problems with the PICC line.

Discussion

Understandability and actionability of patient education materials

The source of the patient education materials examined was related to PEMAT scores. The materials that scored highest on the PEMAT (PICC line care and A second breath) were the longest, providing step-by-step instructions with visual aids. These items were created with input from multiple members of system staff informed by assessment of patient education needs. In contrast, the materials that scored lower on the PEMAT were developed by a vendor external to the system and provided generic information about the health conditions described. For example, vendor materials recommend calling 911 or your doctor to seek medical attention, in the absence of a specific phone number for the system. Vendor items were two or three pages long, had no visual aids (with one exception), and provided general information about PICC lines and tracheostomy care. After Visit Summaries generated the lowest understandability scores and actionability scores equal to those of the vendor. Each clinician retains complete control of the content of these text-only documents, with no template or guidance to promote consistency of the information. As a result, the After Visit Summaries have the potential to contain information tailored to each patient; however, the format of the information and vocabulary used may hinder understanding of the material. In addition, the understandability and actionability of these documents is likely to vary greatly by provider.

The presence of visual aids was also associated with PEMAT scores of understandability and actionability. Several PEMAT items ask specifically about the presence and nature of visual aids, driving this relationship.

Usability of the PEMAT for assessing patient education materials

The PEMAT was easy to use and generated separate scores for the understandability and actionability of patient education materials. PEMAT items were developed to create objective ratings of patient education materials. However, this analysis found that rating of PEMAT item 12 use of visual cues to draw attention to key points) was unstable over time. This issue was addressed by re-rating item 12 for all materials in one sitting.

Using the PEMAT to assess patient education about vocal cord paralysis, Balakrishnan, Chandy, Hseih, Bui, & Verma (2016) also noted a concern about the objectivity of a PEMAT question. Specifically, this study speculated that assessment of PEMAT item #3 (use of common, everyday language) may be subjective and influenced by the rater's "education level, native language, and medical background" (Balakrishnan, Chandy, Hseih, Bui, & Verma, 2016, p, 463). However, this concern was largely unfounded based on strong inter-rater reliability observed among users of varying education and medical background in two studies (Balakrishnan, Chandy, Hseih, et al., 2016; Balakrishnan, Chandy, & Verma, 2016).

These concerns about potential subjectivity of PEMAT ratings could be remedied with the use of multiple raters as implemented by several other studies (Balakrishnan, Chandy, Hseih, et al., 2016; Balakrishnan, Chandy, & Verma, 2016; McClure, Ng, Vitzthum, & Rudd, 2016; Patel et al., 2015; Zellmer, Zimdars, Parker, & Safdar, 2015). In addition, two clinicians reviewing the study results raised a concern that the PEMAT does not address the length of patient education materials, which could influence understandability and actionability of materials. Specifically, the clinicians observed that patients do not continue to engage in materials that are more than a few pages in length. Therefore, the highest scoring materials analyzed in this study, which were more than 10 pages long, may not be as effective as shorter materials in educating patients if they are unwilling or unable to maintain attention to the full document.

Consistency of materials reviewed

Overall, the patient education materials for each health condition were consistent. However, not all of the materials for each health condition described the same patient care activities, and the level of detail across materials varied substantially. The materials for burn care were most consistent with each other, using identical terminology, lists of symptoms that require medical attention, and contact information for obtaining medical attention. This consistency may be due to the fact that all patient care for burns is conducted in one inpatient unit and one outpatient clinic, whereas PICC lines and tracheostomy care occur throughout the hospital and various clinics. In addition, the burn center receives a large amount of private funding that supports a strong infrastructure and resources for staff to collaborate to develop standardized materials for their patients. *Methodology used to evaluate consistency of materials*

This study is based on one rater's assessment of four indicators of consistency of materials: (1) content of the instructions provided, (2) terms used to name health conditions, self-care practices, and equipment, (3) Signs or symptoms requiring medical

attention, and (4) contact information to obtain medical attention. Text mining may have provided a more objective analysis of consistency. However, this approach was not feasible, because the patient education materials were obtained in print rather than electronic form.

Limitations

As only one person conducted data collection, abstraction, and analysis, there is the possibility that the results obtained may reflect biases of this individual. However, this potential source of bias was mitigated by the use of a standardized tool to assess understandability and actionability of the materials examined. Text mining may have produced a more objective assessment of the consistency of the patient education materials reviewed.

This study examined educational materials related to patient self-care activities associated with a small number of health conditions provided in a single healthcare system in the Southeastern US. Therefore, the findings of this study may not generalize to patient education materials targeting different health conditions or used by other healthcare providers.

Implications

The project results will be used by the health system under study to assess the need for revision of patient education materials in use at selected facilities for a sample of conditions and self-care practices. In this way, the study represents a step in a quality improvement cycle, i.e. collecting data to identify potential areas for improvement (Institute for Health Care Improvement, 2016). In addition, the study methods may be

used to conduct a broader evaluation of patient education materials across the health system.

Future studies may further assess the effectiveness of using the PEMAT to assess compliance of patient education materials with health literacy standards when used by individuals of varying levels of education and medical background, as well as analyzing education materials for different health conditions used across the continuum of care.

References

- Agency for Healthcare Research and Quality. (2016). CMS Quality Strategy 2016. Retrieved from <u>http://www.ahrq.gov/workingforquality/agencyplans/2016-cms-agency-specific-plan.pdf</u>
- Arbaje, A. I., Wolff, J. L., Yu, Q., Powe, N. R., Anderson, G. F., & Boult, C. (2008). Postdischarge environmental and socioeconomic factors and the likelihood of early hospital readmission among community-dwelling Medicare beneficiaries. *Gerontologist*, 48(4), 495-504.
- Avalere Health, A. H. A. (2015). *TrendWatch Chartbook 2015: Trends Affecting Hospitals and Health Systems*. Retrieved from Washington, DC: <u>http://www.aha.org/research/reports/tw/chartbook/2015/tableofcontents.pdf</u>
- Balakrishnan, V., Chandy, Z., Hseih, A., Bui, T. L., & Verma, S. P. (2016). Readability and Understandability of Online Vocal Cord Paralysis Materials. *Otolaryngol Head Neck Surg*, 154(3), 460-464. doi:10.1177/0194599815626146
- Balakrishnan, V., Chandy, Z., & Verma, S. P. (2016). Are Online Zenker's Diverticulum Materials Readable and Understandable? *Otolaryngol Head Neck Surg.* doi:10.1177/0194599816655302
- Ball, L. K. (2013). Who should be teaching patients to self-cannulate? *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association*, 40(1), 27; quiz 28.
- Barnett, M. L., Hsu, J., & McWilliams, J. M. (2015). Patient Characteristics and Differences in Hospital Readmission Rates. *Jama Internal Medicine*, 175(11), 1803-1812. doi:10.1001/jamainternmed.2015.4660
- Bhole, M. V., Burton, J., & Chapel, H. M. (2008). Self-infusion programmes for immunoglobulin replacement at home: feasibility, safety and efficacy. *Immunol Allergy Clin North Am*, 28(4), 821-832, ix. doi:10.1016/j.iac.2008.06.005
- Block, L., Morgan-Gouveia, M., Levine, R. B., & Cayea, D. (2014). We could have done a better job: a qualitative study of medical student reflections on safe hospital discharge. J Am Geriatr Soc, 62(6), 1147-1154. doi:10.1111/jgs.12783

- Bravo, B. N., Postigo, J. M., Segura, L. R., Selva, J. P., Trives, J. J., Corcoles, M. J., ...
 Hidalgo, J. L. (2010). Effect of the evaluation of recall on the rate of information recalled by patients in Primary Care. *Patient Educ Couns*, *81*(2), 272-274. doi:10.1016/j.pec.2010.01.02210.1016/j.pec.2010.01.022. Epub 2010 Mar 1.
- Brega, A. G., Barnard, J., Mabachi, N. M., Weiss, B. D., Darren A. DeWalt, M., Brach, C., West, D. R. (2015). *Health Literacy Universal Precautions Toolkit, 2nd edition.* Retrieved from Rockville, MD:
- Bueno, H., Ross, J. S., Wang, Y., Chen, J., Vidán, M. T., Normand, S.-L. T., . . . Krumholz, H. M. (2010). Trends in length of stay and short-term outcomes among Medicare patients hospitalized for heart failure, 1993-2006. *JAMA*, 303(21), 2141-2147. doi:10.1001/jama.2010.748
- Cain, C. H., Neuwirth, E., Bellows, J., Zuber, C., & Green, J. (2012). Patient experiences of transitioning from hospital to home: an ethnographic quality improvement project. *Journal of Hospital Medicine*, 7(5), 382-387. doi:10.1002/jhm.1918
- Centers for Disease Control and Prevention. (2015, November 10, 2015). The CDC Clear Communication Index. Retrieved from <u>http://www.cdc.gov/ccindex/index.html</u>
- Chen, Y.-C., Wang, Y.-C., Chen, W.-K., Smith, M., Huang, H.-M., & Huang, L.-C. (2013). The effectiveness of a health education intervention on self-care of traumatic wounds. *Journal of Clinical Nursing (J CLIN NURS), Sep2013*, 2013. doi:http://dx.doi.org.libproxy.lib.unc.edu/10.1111/j.1365-2702.2012.04295.x
- Ciciriello, S., Johnston, R. V., Osborne, R. H., Wicks, I., deKroo, T., Clerehan, R., . . . Buchbinder, R. (2016). Multimedia educational interventions for consumers about prescribed and over-the-counter medications. doi:10.1002/14651858.CD008416.pub2
- Cox, J. A., & Westbrook, L. J. (2005). Home infusion therapy: essential characteristics of a successful education process: grounded theory study. J Infus Nurs, 28(2), 99-107.
- Davies, N., Papa, N., Ischia, J., Bolton, D., & Lawrentschuk, N. (2015). Consistency of written post-operative patient information for common urological procedures. *Anz Journal of Surgery*, 85(12), 941-945. doi:10.1111/ans.13106
- DeWalt, D. A., Callahan, L. F., Hawk, V. H., Broucksou, K. A., Hink, A., Rudd, R., & Brach, C. (2010). *Health Literacy Universal Precau- tions Toolkit (AHRQ Publication No. 10–0046-EF)*. Retrieved from Rockville, MD: <u>http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html</u>

- Doak, C. C., Doak, L., G., & Root, J. H. (1996). *Teaching Patients with Low Literacy Skills* (2nd ed.). Philadelphia, PA: J.B. Lippincott Company.
- Fagermoen, M. S., & Hamilton, G. (2006). Patient information at discharge--a study of a combined approach. *Patient Educ Couns*, 63(1-2), 169-176. doi:10.1016/j.pec.2005.09.016
- Frank-Bader, M., Beltran, K., & Dojlidko, D. (2011). Improving transplant discharge education using a structured teaching approach. *Progress in Transplantation* (Aliso Viejo, Calif.), 21(4), 332-339.
- Fredericks, S., Sidani, S., & Shugurensky, D. (2008). The effect of anxiety on learning outcomes post-CABG. *The Canadian Journal of Nursing Research = Revue Canadienne De Recherche En Sciences Infirmières*, 40(1), 127-140.
- Gershenson, T. A., Quon, H., Somerville, S., & Cohn, E. (1999). Tilling the soil: nurturing the seeds of patient and family education. *J Nurs Care Qual*, *13*(6), 83-91.
- Giuse, N. B., Koonce, T. Y., Storrow, A. B., Kusnoor, S. V., & Ye, F. (2012). Using health literacy and learning style preferences to optimize the delivery of health information. *Journal of Health Communication*, *17 Suppl 3*, 122-140. doi:10.1080/10810730.2012.712610
- Gorski, L. A. (2010). Central venous access device associated infections: recommendations for best practice in home infusion therapy. *Home Healthc Nurse*, 28(4), 221-229. doi:10.1097/NHH.0b013e3181d6c3ad
- Houts, P. S., Doak, C. C., Doak, L., G., & Loscalzo, M. J. (2006). The role of pictures in improving health communication: A review of research on attention, comprehension, recall, and adherence. 61(2), 173–190. doi:10.1016/j.pec.2005.05.004
- Inott, T., & Kennedy, B. B. (2011). Assessing learning styles: practical tips for patient education. *Nurs Clin North Am*, 46(3), 313-320, vi. doi:10.1016/j.cnur.2011.05.006
- Johnson, A., Sandford, J., & Tyndall, J. (2003). Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home. *Cochrane Database Syst Rev*(4), Cd003716. doi:10.1002/14651858.cd003716
- Kaboli, P. J., Go, J. T., Hockenberry, J., Glasgow, J. M., Johnson, S. R., Rosenthal, G. E.,... Vaughan-Sarrazin, M. (2012). Associations between reduced hospital length of stay and 30-day readmission rate and mortality: 14-year experience in 129

Veterans Affairs hospitals. *Annals of Internal Medicine*, *157*(12), 837-845. doi:10.7326/0003-4819-157-12-201212180-00003

- Kalisch, B. J., McLaughlin, M., & Dabney, B. W. (2012). Patient perceptions of missed nursing care. Jt Comm J Qual Patient Saf, 38(4), 161-167.
- Kemp, E. C., Floyd, M. R., McCord-Duncan, E., & Lang, F. (2008). Patients prefer the method of "tell back-collaborative inquiry" to assess understanding of medical information. *J Am Board Fam Med*, 21(1), 24-30. doi:10.3122/jabfm.2008.01.07009310.3122/jabfm.2008.01.070093.
- Koh, H. K., & Rudd, R. E. (2015). The Arc of Health Literacy. *JAMA*, *314*(12), 1225-1226. doi:10.1001/jama.2015.9978
- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy*. Retrieved from <u>https://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2006483</u>
- Lapum, J., Angus, J. E., Peter, E., & Watt-Watson, J. (2011). Patients' discharge experiences: returning home after open-heart surgery. *Heart & Lung: The Journal of Critical Care, 40*(3), 226-235. doi:10.1016/j.hrtlng.2010.01.001
- Marbach, T. J., & Griffie, J. (2011). Patient Preferences Concerning Treatment Plans, Survivorship Care Plans, Education, and Support Services. Oncology Nursing Forum (ONCOL NURS FORUM), May2011. doi:http://dx.doi.org.libproxy.lib.unc.edu/10.1188/11.ONF.335-342
- McCaskey, M. S. (2009). Preventing catheter-related bloodstream infections: a pediatric case study. *Home Healthc Nurse*, 27(2), 124-126. doi:10.1097/01.nhh.0000346317.38831.38
- McClure, E., Ng, J., Vitzthum, K., & Rudd, R. (2016). A Mismatch Between Patient Education Materials About Sickle Cell Disease and the Literacy Level of Their Intended Audience. *Prev Chronic Dis*, 13, E64. doi:10.5888/pcd13.150478
- Mudge, A. M., Shakhovskoy, R., & Karrasch, A. (2013). Quality of transitions in older medical patients with frequent readmissions: Opportunities for improvement. *European Journal of Internal Medicine*, 24(8), 779-783. doi:10.1016/j.ejim.2013.08.708
- Nicolson, D., Knapp, P., Raynor, D. K., & Spoor, P. (2009). Written information about individual medicines for consumers. *Cochrane Database of Systematic Reviews*(2), 66. doi:10.1002/14651858.CD002104.pub3

- Office of Disease Prevention and Health Promotion at U.S. Department of Health and Human Services. (2010). *National Action Plan to Improve Health Literacy*. Retrieved from Washington, DC:
- Patel, S. K., Gordon, E. J., Wong, C. A., Grobman, W. A., Goucher, H., & Toledo, P. (2015). Readability, Content, and Quality Assessment of Web-Based Patient Education Materials Addressing Neuraxial Labor Analgesia. *Anesth Analg*, 121(5), 1295-1300. doi:10.1213/ANE.00000000000888
- Peter, D., Robinson, P., Jordan, M., Lawrence, S., Casey, K., & Salas-Lopez, D. (2015). Reducing Readmissions Using Teach-Back. *Journal of Nursing Administration (J NURS ADM), Jan2015.* doi:http://dx.doi.org.libproxy.lib.unc.edu/10.1097/NNA.00000000000155
- Pieper, B., Sieggreen, M., Nordstrom, C. K., Freeland, B., Kulwicki, P., Frattaroli, M., . . Bednarski, D. (2007). Discharge knowledge and concerns of patients going home with a wound. *J Wound Ostomy Continence Nurs*, *34*(3), 245-253; quiz 254-245. doi:10.1097/01.won.0000270817.06942.00
- Polzien, G. (2006). Home infusion therapy. First things first: the patient and the prevention of central catheter infections. *Home Healthc Nurse*, 24(10), 681-684.
- Selic, P., Svab, I., Repolusk, M., & Gucek, N. K. (2011). What factors affect patients' recall of general practitioners' advice? *BMC Fam Pract*, 12, 141. doi:10.1186/1471-2296-12-14110.1186/1471-2296-12-141.
- Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education Materials Assessment Tool (PEMAT): a new measure of understandability and actionability for print and audiovisual patient information. *Patient Educ Couns*, 96(3), 395-403. doi:10.1016/j.pec.2014.05.027 s10.1016/j.pec.2014.05.027. Epub 2014 Jun 12.
- Shoemaker, S. J. W., Michael S.; Brach, C. (2013). The Patient Education Materials Assessment Tool (PEMAT) and User's Guide. Retrieved from <u>http://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-</u><u>mgmt/pemat/index.html</u>
- Stephenson, P. L. (2006). Before the teaching begins: Managing patient anxiety prior to providing education. *Clinical Journal of Oncology Nursing*, 10(2), 241-245. doi:10.1188/06.CJON.241-245
- Weiss A.J. and Elixhauser, A. (2014). Overview of Hospital Stays in the United States, 2012. HCUP Statistical Brief #180. Retrieved from Rockville, MD: <u>http://www.hcup-us.ahrq.gov/reports/statbriefs/sb180-Hospitalizations-United-States-2012.pdf</u>.

- Wennberg, J. E. (1996). *The Dartmouth Atlas of Health Care in the United States*. Chicago, IL: American Hospital Publishing Inc.
- Wennberg, J. E. (2010). *Tracking Medicine: A Researcher's Quest to Understand Health Care*. New York, NY: Oxford University Press.
- Zellmer, C., Zimdars, P., Parker, S., & Safdar, N. (2015). Evaluating the usefulness of patient education materials on surgical site infection: a systematic assessment. Am J Infect Control, 43(2), 167-168. doi:10.1016/j.ajic.2014.10.020
- Zeng-Treitler, Q., Kim, H., & Hunter, M. (2008). Improving patient comprehension and recall of discharge instructions by supplementing free texts with pictographs. *AMIA Annu Symp Proc*, 849-853.

Appendix. Patient Education Materials Assessment Tool for Printable Materials (PEMAT_P)

Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P)

How To Use the PEMAT To Assess a Material

There are seven steps to using the PEMAT to assess a patient education material. The instructions below assume that you will score the PEMAT using paper and pen. If you use the **PEMAT Auto-Scoring Form**, a form that will automatically calculate PEMAT scores once you enter your ratings, you can skip Step 5. The form is available at: http://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/index.html.

Step 1: Read through the PEMAT and User's Guide. Before using the PEMAT, read through the entire User's Guide and instrument to familiarize yourself with all the items. In the User's Guide a (P) and (A/V) are listed after an item to indicate whether it is relevant to print and audiovisual materials, respectively.

Step 2: Read or view patient education material. Read through or view the patient education material that you are rating in its entirety.

Step 3: Decide which PEMAT to use. Choose the PEMAT-P for printable materials or the PEMAT-A/V for audiovisual materials.

Step 4: Go through each PEMAT item one by one. All items will have the answer options "Disagree" or "Agree." Some—but not all—items will also have a "Not Applicable" answer option. Go one by one through each of the items, 24 for printable materials and 17 for audiovisual materials, and indicate if you agree or disagree that the material meets a specific criterion. Or, when appropriate, select the "Not Applicable" option.

You may refer to the material at any time while you complete the form. You don't have to rely on your memory. Consider each item from a patient perspective. For example, for "Item 1: The material makes its purpose completely evident," ask yourself, "If I were a patient unfamiliar with the subject, would I readily know what the purpose of the material was?"

Step 5: Rate the material on each item as you go. After you determine the rating you would give the material on a specific item, enter the number (or N/A) that corresponds with your answer in the "Rating" column of the PEMAT. Do not score an item as "Not Applicable" unless there is a "Not Applicable" option. Score the material on each item as follows:

| If Disagree | Enter 0 |
|-------------------|-----------|
| If Agree | Enter 1 |
| If Not Applicable | Enter N/A |

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Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P)

Additional Guidance for Rating the Material on Each Item (Step 5)

- Rate an item "Agree" when a characteristic occurs throughout a material, that is, nearly all of the time (80% to 100%). Your guiding principle is that if there are obvious examples or times when a characteristic could have been met or could have been better met, then the item should be rated "Disagree." The User's Guide provides additional guidance for rating each item.
- Do not skip any items. If there is no "Not Applicable" option, you must score the item 0 (Disagree) or 1 (Agree).
- Do not use any knowledge you have about the subject before you read or view the patient education material. Base your ratings ONLY on what is in the material that you are rating.
- Do not let your rating of one item influence your rating of other items. Be careful to rate each item separately and distinctly from how you rated other items.
- If you are rating more than one material, focus only on the material that you are reviewing and do not try to compare it to the previous material that you looked at.

Step 6: Calculate the material's scores. The PEMAT provides two scores for each material one for understandability and a separate score for actionability. Make sure you have rated the material on every item, including indicating which items are Not Applicable (N/A). Except for Not Applicable (N/A) items, you will have given each item either 1 point (Agree) or 0 points (Disagree). To score the material, do the following:

- Sum the total points for the material on the understandability items only.
- *Divide the sum by the total possible points*, that is, the number of items on which the material was rated, excluding the items that were scored Not Applicable (N/A).
- *Multiply the result by 100* and you will get a percentage (%). This percentage score is the understandability score on the PEMAT.
 - Example: If a print material was rated Agree (1 point) on 12 understandability items, Disagree (0 points) on 3 understandability items, and N/A on one understandability item (N/A), the sum would be 12 points out of 15 total possible points (12 + 3, excluding the N/A item). The PEMAT understandability score is 0.8 (12 divided by 15) multiplied by 100 = 80%.

To score the material on actionability, repeat Step 6 for the actionability items.

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Step 7: Interpret the PEMAT scores. The higher the score, the more understandable or actionable the material. For example, a material that receives an understandability score of 90% is more understandable than a material that receives an understandability score of 60%, and the same goes for actionability. If you use the PEMAT to rate the understandability and actionability of many materials, you may get a sense of what score indicates exceptionally good or exceptionally poor materials.

Title of Material:

Name of Reviewer:

Review Date:

Read the PEMAT User's Guide (available at: http://www.ahrq.gov/professionals/preventionchronic-care/improve/self-mgmt/pemat/) before rating materials.

UNDERSTANDABILITY

| Item # | Item | Response Options | Rating | | | |
|-----------------------|--|--|--------|--|--|--|
| Topic: C | Content | | | | | |
| 1 | The material makes its purpose completely evident. | Disagree=0, Agree=1 | | | | |
| 2 | The material does not include information or content that distracts from its purpose. | Disagree=0, Agree=1 | | | | |
| Topic: V | Topic: Word Choice & Style | | | | | |
| 3 | The material uses common, everyday language. | Disagree=0, Agree=1 | | | | |
| 4 | Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined. | Disagree=0, Agree=1 | | | | |
| 5 | The material uses the active voice. | Disagree=0, Agree=1 | | | | |
| Topic: Use of Numbers | | | | | | |
| 6 | Numbers appearing in the material are clear and easy to understand. | Disagree=0, Agree=1, No numbers=N/A | | | | |
| 7 | The material does not expect the user to perform calculations. | Disagree=0, Agree=1 | | | | |
| Topic: (| Organization | | | | | |
| 8 | The material breaks or "chunks" information into short sections. | Disagree=0, Agree=1, Very short material [*] =N/A | | | | |
| 9 | The material's sections have informative headers. | Disagree=0, Agree=1, Very short material [*] =N/A | | | | |
| 10 | The material presents information in a logical sequence. | Disagree=0, Agree=1 | | | | |
| 11 | The material provides a summary. | Disagree=0, Agree=1, Very short material [*] =N/A | | | | |
| Topic: I | Topic: Layout & Design | | | | | |
| 12 | The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points. | Disagree=0, Agree=1 Video=N/A | | | | |

^{*}A very short print material is defined as a material with two or fewer paragraphs and no more than 1 page in length.

Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P)

| Item # | Item | Response Options | Rating | | |
|--------|---|--|--------|--|--|
| Topic: | Topic: Use of Visual Aids | | | | |
| 15 | The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size). | Disagree=0, Agree=1 | | | |
| 16 | The material's visual aids reinforce rather than distract from the content. | Disagree=0, Agree=1, No visual aids=N/A | | | |
| 17 | The material's visual aids have clear titles or captions. | Disagree=0, Agree=1, No visual aids=N/A | | | |
| 18 | The material uses illustrations and photographs that are clear and uncluttered. | Disagree=0, Agree=1, No visual aids=N/A | | | |
| 19 | The material uses simple tables with short and clear row and column headings. | Disagree=0, Agree=1, No tables=N/A | | | |

Total Points: _____

Total Possible Points: _____

Understandability Score (%): _____

(Total Points / Total Possible Points) × 100

ACTIONABILITY

| Item # | Item | Response Options | Rating |
|--------|---|----------------------|--------|
| 20 | The material clearly identifies at least one action | Disagree=0, Agree=1 | |
| | the user can take. | | |
| 21 | The material addresses the user directly when | Disagree=0, Agree=1 | |
| | describing actions. | | |
| 22 | The material breaks down any action into | Disagree=0, Agree=1 | |
| | manageable, explicit steps. | | |
| 23 | The material provides a tangible tool (e.g., menu | Disagree=0, Agree=1 | |
| | planners, checklists) whenever it could help the | | |
| | user take action. | | |
| 24 | The material provides simple instructions or | Disagree=0, Agree=1, | |
| | examples of how to perform calculations. | No calculations=NA | |
| 25 | The material explains how to use the charts, | Disagree=0, Agree=1, | |
| | graphs, tables, or diagrams to take actions. | No charts, graphs, | |
| | | tables, or | |
| | | diagrams=N/A | |
| 26 | The material uses visual aids whenever they | Disagree=0, Agree=1 | |
| | could make it easier to act on the instructions. | | |

Total Points: _____

Total Possible Points:

Actionability Score (%): _____

(Total Points / Total Possible Points) × 100

50

4

Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P)