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Sanzida Anzuman
University of Southern Maine, Muskie School of Public Service

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Developing Recommendations to Prepare Individualized and Low Health Literacy Appropriate Health Education Material for Stroke Patients

Sanzida Anzuman

Muskie School of Public Service, University of Southern Maine

Advisor: Brenda Joly, PhD, MPH

Second Reader: Mary Philbrick, MSEd, BSN, RN, CCRN

**Developing Recommendations to Prepare Individualized and Low Health Literacy
Appropriate Health Education Material for Stroke Patients**

Background: According to the Center for Disease Control and Prevention (CDC), stroke is the fifth leading cause of death and leading cause of long-term disability in the United States. Each year, approximately 800,000 people suffer from stroke; among them about 600,000 strokes are first attack and about 200,000 are recurrent stroke (CDC, 2017).

Stroke patients often get readmitted to the hospital due to various causes including recurrent stroke, infection, medication side effects etc. Currently 30-day readmission rate for stroke is 8.7% nationwide. From July 2014 to June 2017, readmission rate for stroke in Central Maine Medical Center (CMMC) was around 10% which improved to around 7% for current 2018 data (January to August, 2018) (CMMC internal data source). Effective patient education is a critical part of preventing hospital readmission for stroke patients.

For stroke, known risk factors include high blood pressure, diabetes, abnormal lipid profile, smoking, drinking alcohol, obesity, lack of exercise, history of previous stroke and heart attack (CDC, 2017). Patient education should be aimed to reduce individual risk and to train patients to manage their medications, disabilities, and lifestyle. Several studies revealed that patient education is more effective with individualized approach than generalized passive approach (Oliver, Kravitz, Kaplan, & Meyers, 2001 and Sullivan & Katajamaki, 2009). According to the Health Belief Model, beliefs associated with health behavior change include illness severity, susceptibility, perceived benefits, and barriers of taking action (Sullivan & Katajamski, 2009). Individualized patient education is more effective than generalized patient education to change patients' belief and knowledge about their health condition and to improve health outcome

Recommendations to Individualize and Improve Health Literacy of Patient Education Material

(Sullivan & Katajamaki, 2009). A recent survey by the Joint Commission also recommended CMMC to offer stroke patients individualized education that is more appropriate and effective for patients.

Another important feature of patient education is using appropriate health literacy for general population. Average Americans read at eighth grade level but health information is usually offered at college level (The AMA Foundation, 2010). Low health literacy is strongly associated with poorer use of health care and poorer health outcomes, leading to more emergency visits (Shoemaker, Wolf, & Brach, 2014). According to the American Heart Association, patient education can't be one-size-fits-all; health information should be tailored to a patient's ability to understand and keep them motivated to maintain their health and reduce their health related risk factors (American Health Association, 2017). It is imperative that health care providers educate patients and caregivers using language that they can process and understand to make appropriate health decision when needed.

Purpose of the Capstone: The purpose of this capstone was to review CMMC's current patient education material for stroke patients and to recommend changes to prepare individualized patient education material that will specifically address health condition, risk factors and lifestyle modifications for individual patient. This capstone project was also aimed to review CMMC's current patient education material for stroke patients and to offer recommendations to improve health literacy for patients with low health literacy.

Research Questions:

- How can the current patient education material used by CMMC for stroke patients be individualized?

Recommendations to Individualize and Improve Health Literacy of Patient Education Material

- How can the current patient education material used by CMMC for stroke patients be more appropriate and understandable for patients with low health literacy?

Audience: The target audience for this capstone is CMMC employees who are involved in stroke patient education and quality improvement.

Methods:

Literature Review: The CDC website was used to gather statistical information including current statistics about national stroke incidence, recurrence rate for stroke, and total national annual cost due to stroke. The literature review included peer reviewed articles on benefit of individualized patient education over generalized patient education, nursing empowerment for patient education, tools and methods for individualized patient education and improved health literacy. Online Journal databases such as Medline, PubMed, PsycINFO, Wiley Online Library, and Google Scholar have been used to gather articles. Also several websites including CDC, American Heart Association, Agency for Healthcare Research and Quality, and Harvard T. H. Chan, School of Public Service have been searched for tools and recommendations to individualize patient education and improve health literacy.

Institutional Review Board Approval: In order to continue this capstone project, approval from University of Southern Maine (USM) Institutional Review Board (IRB) was required. The necessary form from the USM Office of Research Integrity and Outreach (ORIO) Human Research Protection Program was completed. Mary Philbrick, the CMMC preceptor submitted a letter in compliance with ORIO to assure that she would supervise the capstone activities in CMMC.

Recommendations to Individualize and Improve Health Literacy of Patient Education Material

Preparation of Recommendations: According to the capstone proposal, Mary Philbrick had an informal conversation with nurses involved in educating stroke patients in CMMC. Currently CMMC is using a booklet prepared by Krames Patient Education a Product of Staywell to educate stroke patients. They also provide brochures in addition to this booklet for more information on specific topic such as smoking, weight loss etc. In that conversation nurses shared their barriers and needs to implement individualized patient education. They shared that they need guidance to implement individualized patient education and a practical example using the current booklet that is being used in CMMC would be very helpful for them. Preparing a booklet with a clinical scenario would offer them a guidance to individualize the booklet.

After receiving IRB approval and permission to contact researchers, several researchers who have worked on individualizing patient education were contacted. A careful review of the literatures and discussion with researchers directed the course of the capstone which was slightly different than the proposal. Since CMMC is currently using a booklet, there was not much opportunity to incorporate changes according to the best practice literature to individualize patient education. However, CMMC can consider implementing best practice guidelines in the future depending on resources and time. Thus recommendations were prepared with three different focuses:

- Recommendations to individualize current patient education material used for CMMC stroke patients
- Recommendations to improve health literacy of current patient education material used for CMMC stroke patients
- Future recommendations to implement evidence-based individualized education to CMMC stroke patients

Recommendations to individualize current patient education material used for CMMC stroke patients:

Following the conversation with CMMC nurses, Mary Philbrick suggested to create a clinical scenario of a stroke patient who has some risk factors and disabilities from stroke and prepare a booklet individualizing education for that patient specifically. A clinical scenario has been created which is described below. This clinical scenario has been used as an example during recommendations preparation.

"*Mr. Jones is 75 years old white male. He is retired and lives in home with his wife. He is a smoker and has never tried to quit. Mr. Jones does not drink alcohol. He does not exercise but he has been taking care of his home and backyard. He eats vegetable but he prefers meat and junk food. He has high blood pressure, diabetes and abnormal lipid profile. His basal metabolic rate (BMI) is 27.*

He was admitted to CMMC with ischemic stroke and received the recommended treatment. During his stroke, he developed mild left-sided weakness. He also developed depression after his stroke. During his hospital stay he received rehabilitative care and his muscle weakness is improving. He has mild memory and cognitive impairment. He is planning to return home and drive, if possible. Mrs. Jones, who is 73 years old retired white female, has high blood pressure, diabetes, and osteoarthritis; she is planning to take care of him. Their children live far from them. They have friends and neighbors on whom they can depend for help".

- The key to offer individualized patient education is to offer health information related to them. To provide individualized patient education it is crucial to know every patient individually. This can be done in two ways: a) carefully reviewing patient chart and b)

asking questions to patients on every topic to address their readiness to adopt the planned lifestyle, goals, preferences and dislikes, barriers, and supports. Research finds that people are more likely to actively and thoughtfully process information if they perceive it to be personally relevant (Kreuter & Holt, 2001).

- Adding individual patient's name on top/ beginning of the education material can make the material personalized. It will draw patient's attention and will create a sense that the education material is specifically made for that person (Kreuter & Holt, 2001).

Since this booklet is being used as a guide for patient, including each patient's necessary personal information will make the booklet more personal. Personal information should include advance directive- do not resuscitate (DNR), medical power of attorney (MPOA), important medical diagnosis, important daily activities, and emergency contact information. All this information in one place will help patients and also providers to know the patients and follow through easily.

For Mr. Jones the first page should be:

Name: Mr. Jones

Date of Birth: 8/12/1943

DNR: Yes

MPOA: Mrs. Jones

Important medical diagnosis: High blood pressure, diabetes, abnormal lipid profile

Important daily activities:

- Take medicine regularly at right time and dose,

- Eat vegetable and fruit one serving more than before,

- Walk X steps daily

- Decrease number of daily consumed cigarettes than before

Emergency contact information: xxx-xxx-xxxx (Mrs. Jones cell phone number)

- During the process of providing general information, provide additional information about specific patient. For example, while educating patients about stroke and types mention type of stroke that individual patient had and what area of the brain was affected, the challenges usually patients face after stroke affecting that specific area. This way patient will be able to correlate his or her condition with generalized information.

- For every topic try to gather some individualized feedback from every patient by asking about individual goal, preference, expectations, strategies, and barriers. Along with providing more information/hand out about that specific topic, set specific goals for individual patient, document them, and discuss ways to address individual patients' barriers and offer specific support.

For example, since Mr. Jones has left sided weakness, he is relearning to walk after stroke with walker, set a daily goal for taking certain amount of steps and timing that reflects his preference. Also address individual barriers while making plan and setting goal. For

example, Mr. Jones needs walker and he does not have it home, offer suggestion/ help and make plan accordingly with available resources.

- According to the Health Belief Model, beliefs associated with health behavior change include illness severity, susceptibility, perceived benefits, and barriers of taking action (Sullivan & Katajamski, 2009). Research suggests that personal belief and degree of readiness are very important to create desired change in lifestyle. Before educating patients about lifestyle modification, ask patients about their belief and thoughts about that specific change and try to understand their mental readiness, educate and set goals accordingly. For example, to counsel Mr. Jones to quit smoking, it is important to know his perception about smoking and readiness to quit. A person who has tried several times to quit smoking will consider quitting smoking differently than a person has never thought to quit smoking. Therefore, their education, action plan and goals should be different. Mr. Jones has been smoking for most part of his life and never thought of quitting. He needs education on smoking that will prepare him to think about quitting smoking and decrease the number of daily cigarettes rather than totally stopping smoking.

- Provide additional information, charts, and tables to individual patient about specific topic. For example, provide chart for normal range of blood pressure, blood sugar, cholesterol level and relate normal range with their lab values. This way patient will be able to understand their health condition and have idea about desired change to make.

- Cross out irrelevant portions for individual patient and write on top "Not necessary for you". Since Mr. Jones does not have speech problem, cross out the "Aphasia" section and write "not necessary for you" on top of this section.

- Many elderly people don't know where to go or contact when they need help. Filling out the Resource directory according to individual patient's need will help patients to access their needed resources. For example, Mr. and Mrs. Jones are now considering home health aide or housekeeping help to do household work. Also, a respite care would be helpful for Mrs. Jones. Therefore, filling out information about nearby home health agency and respite care would be helpful for them.

- Gather information about contextual factors such as caregiver and social support, transportation, cultural background, and spiritual belief for every patient as much as possible. Contextual factors are unique to patients and are relevant to their care and achieving goals (Weiner, 2004). Prepare care plan and set goals accordingly. For example, before counseling patient to eat healthy, ask about patient's dietary habits, preferences, dislikes and assess their readiness to change eating style. Counsel them accordingly, set goals, and write it down. Also, assess barriers to eating healthy such as financial issues, inability to go to grocery store, inability to cook etc. and set goals keeping these barriers in mind along with offering solutions to the barriers. Mr. Jones does not like vegetables and consumes mostly unhealthy food. Mr. and Mrs. Jones avoid driving to grocery store in winter season and buy frozen processed food during their trips so they can skip going to grocery store and cooking at home. Mr. Jones needs education to prepare him to eat healthier along with suggestions for meal preparation. Recently many grocery stores deliver food to home; providing information about these services will help Mr. Jones.

- Caregivers are different depending on situation and their challenges are different too. Know about patient's caregivers. Assess caregivers' physical and mental condition,

> responsibilities, social support, and barriers as these factors will affect patient care, offer support/ solution to barriers and plan patient care plan accordingly. Mrs. Jones has high blood pressure, diabetes, and osteoarthritis. Even though she has been managing her health well and she can manage Mr. Jones's medicine, she cannot help Mr. Jones for walking and exercising. They need home health aide to support Mr. Jones until he gains full strength in his left side of body. Also home health aide or respite care will offer Mrs. Jones some personal time, going out and enjoy time with friends and will prevent depression and caregiver burnout for Mrs. Jones.

- Encourage patient and their family member to ask questions. Recently an ongoing Comprehensive Post-Acute Stroke Services (COMPASS) Study in North Carolina is using three questions on four different domains:

  1. What are my health concerns? [both clinical and nonclinical health factors affecting health, independence, and recovery]

  2. Why is this important to me? [Importance of each area of concern]

  3. How do I find my way forward? [Recommendations for self-management and referrals consistent with individual's needs, goals, and preferences] (Bushnell et al, 2018).

Basically having a good understanding of these questions on every topic for every patient will make patient education individualized.

- Research suggests that using a checklist improves patient safety, communication and team work (Sewell et al, 2011). Using a checklist for patient education will help nurses to keep track of covered topics and help patients to understand topics important for them. Thus a checklist has been created and included in Appendix A.

11

Recommendations to Individualize and Improve Health Literacy of Patient Education Material

A current CMMC booklet was prepared with the described clinical scenario to offer a practical example of individualizing education material for stroke patients. This was done by writing in the booklet, filling out tables, checking appropriate boxes, and crossing unnecessary portion in the booklet according to the clinical scenario. The recommendations and checklist have been attached in that booklet along patient's personal information at the beginning of the booklet.

Recommendations to Improve Health Literacy of Current CMMC Patient Education Material for Stroke Patients:

- **CDC Plain Language guideline:** The current booklet for stroke education has been reviewed for compliance with CDC Plain language guideline. The booklet mostly follows the guideline as it is written in simple English; several words have been identified as not compliant. Those words have been highlighted using a booklet and more appropriate words according to CDC Plain Language guideline have been written down besides those words (CDC, 2007). After highlighting the booklet for non-complaint words, it was realized that it is difficult to cover all non-complaint words from the booklet since the booklet has total 64 pages. Thus, a list of those non-compliant words has been created (Appendix B) so that nurses know at a glance for which words they need further explanation.

- **PEMAT Guideline:** The booklet has been reviewed for compliance with Patient Education Materials Assessment Tools guideline (Shoemaker, Wolf, & Brach, 2014). The booklet is mostly compliant with PEMAT guideline both for understandability and actionability (Appendix C). PEMAT scoring for printed materials has not been done

since scoring will not help to meet the capstone's purpose. The booklet is not complaint with PEMAT guide in only one topic; the booklet does not provide a short summary at the end of each topic. Providing summary at the end of each topic is not feasible for the booklet as it covers many topics along with specific goals. However, nurses are advised to summarize important topic and use "teach back" method as it is an effective way to assess and confirm patient understanding and train patients to manage their medications and lifestyle (the Agency for Healthcare Research & Quality, 2015).

- **Guidelines for Assessing Materials:** The capstone proposal includes that Harvard T. H. Chan, School of Public Service guidelines for rewriting materials was supposed to be followed to improve health literacy of the booklet. Later, it was found the there is no option to rewrite the booklet. Thus Harvard T. H. Chan, School of Public Service guidelines for assessing materials was used instead of guidelines for rewriting materials to assess the booklet for health literacy (Rudd, no date). The booklet is mostly compliant with the guideline for length of sentences, multi-syllabic words, charts and graphs. However, no scoring formula was applied on the booklet as the booklet is prepared in special PDF format and computerized formula was not applicable for that PDF format.

After preparing recommendation drafts, they were shared with Mary Philbrick and one of the researchers of COMPASS Study to gather feedback about feasibility of these recommendations. Their feedbacks were incorporated into the recommendations.

Future recommendations to provide evidence-based individualized patient education:

- Developing individualized printed patient education material:

Step 1: Analyzing the problem needed to be addressed and understanding its determinants:

It is important to know about the problem, its determinants, and outcome for stroke patients. For stroke, determinants are important risk factors (high blood pressure, diabetes, abnormal lipid profile), life style (smoking, drinking alcohol, and eating unhealthy) and related outcomes are recurrent stroke, readmission, fall, medication side effects etc. Program planning model PRECEDE/ PROCEED provides a useful framework to analyze health problem (The Rural Health Information Hub, no date).

Step 2: Developing an assessment tool:

Individualized patient education is assessment based. As the level of assessment increases, the degree of individualization increases too. A questionnaire or survey can measure related factors. The survey may be self-administered, administered by an interviewer, or by an interactive computer program. Questions should be close-ended, with "yes" or "no" answer. The assessment tool should be developed in a way that the response choices to each question must be known. This step involves identifying appropriate questions and response choices to include in the tailoring assessment.

Step 3: Creating tailored messages:

The assessment tool will provide the framework for developing the tailored message library. The tailored message library is a computer file which consists of all possible elements (both text and

Recommendations to Individualize and Improve Health Literacy of Patient Education Material

graphics) that could be provided to an individual participant. Developing such library is a complex process, a simple one is shown in the table below with example:

Question	Response		Message concepts (Description of each intervention strategy)
	Yes ────→	Intervention strategy	
	No ────→	Intervention strategy	
Have you ever tried to quit smoking?	Yes────→	Self-monitoring, recognition of high risk situation, stimulus control	Monitor how many times you smoke, identify situations when you are likely to smoke, identify strategies to control your stimulus.
	No────→	Importance of quitting smoking, negative health effects of smoking	Explain how smoking is related to heart disease, vascular disease, and stroke

The final versions of all full-length messages are put into the message library, and each message element is assigned a name. For example, a message designed to help smokers deal with a barrier to quitting concerns about self-monitoring might be named "SMOKING. BARRIER. SELF-MONITORING".

Step 4: Developing a database:

Once the assessment has been done, participants' responses must be recorded in a way that can be easily converted into appropriate tailored message. A simpler way to do this is by creating a

computer database with at least one data field for each assessment question. Each question can be assigned a variable name, and each response choice can be assigned a numeric value.

Step 5: Developing tailoring algorithms and a computer program:

This step is to formalize the logic, or decision rules, that link these two entities and write the computer code to automatize the linkage. Tailoring algorithms can be written in pseudo code- a series of "if/then" logic statements that join each assessment response with the appropriate tailored messages. For example, an algorithm might read "if Quit. Smoking. Barrier = 3 then take Barrier. Self-monitoring message from the tailored message library and include it in the tailored quit smoking plan".

When all tailoring algorithms and/or computer code have been created, they must be tested extensively before implementation. Providing wrong message to a person due to tailoring misfire will compromise the integrity and purpose of the program along with harm to the recipient.

Microsoft Word is capable of processing such code. When such code is combined with the message library in the form of a Word document, the document will function as a kind of tailored message generator.

- <u>Developing computer based individualized patient education material:</u>

COMPASS Study is an extensive, ongoing clinical trial conducted by Wake Forest Baptist Medical Center in Winston Salem, North Carolina with 42 participating hospitals. The trial developed questionnaires to capture stroke related factors such as cognitive function, health literacy, medication management and adherence, cardiovascular risk factor management, knowledge of stroke warning signs, caregivers' health, stress and needs. The multidisciplinary

COMPASS team selected questions by reviewing the institute of Medicine's recommendations for social and functional factors to be included in electronic health record (EHR). Final questionnaires are provided in the Data Supplement.

A web-based application was developed that included the script, questions, validation rules, and skip patterns to capture patient- reported-outcomes (PROs) with minimal burden for patients, caregivers, and clinicians. Embedded algorithms within COMPASS integrate and assess electronic data and immediately generate actionable, individualized care plan (CP). In addition, CPs are linked to a stroke-specific Community Resources Directory, systemically created for all counties served by COMPASS hospitals. The Community Resources Directory provides information about local resources that are available to meet a patient's specific social, economic, behavioral, or environmental needs as identified by COMPASS-CP. These supports include home and community based services, disease specific support groups, caregiver support groups, adult day care, transportation, home-delivered meals, and behavioral health services (Duncan et al, 2018).

It is important to note that in this trial, patients fill out questionnaires at two time points: a) 2 days post discharge over phone and b) a clinic visit on 7 to 14 days post discharge. Patient's care plan gets modified each time according to patient's feedback using questionnaires. Also, the trial prepared questions based on four domains (Bushnell et al, 2018):

1. **Numbers**- Know your blood pressure, Hemoglobin A1C, cholesterol etc.
2. **Engage**- Be active in mind, body, and spirit through physical, cognitive, and social activity.

3. **Support**- Seek support for your stress, family stress, finances for medications, and transportation

4. **Willingness**- Be willing to manage your medications and lifestyle.

   Each of these domains addresses three questions:

   1. **What are my health concerns?**

   2. **Why is this important to me?**

   3. **How do I find my way forward?**

   - Having at least one post-discharge assessment by the hospital stroke team:

In CMMC, patient education is offered on the hospital discharge day, that time stroke patients mostly experience many physical and mental issues including muscle weakness, speech problem, swallowing problem, memory loss, and post-stroke fatigue. Their caregiver or family members also go through a lot physical and emotional stress in a very short period of time. Patient and their family member might miss information during that time. Also, after stroke, patients go through a vulnerable situation and health condition and support system can change when they return to their place. After any emergency visit, patients are suggested to follow up with their primary care physician. Many stroke patients do not have any primary care doctor and sometimes it can take long time to have an appointment with them. Since hospital stroke team treats stroke patients and develops care plan, and they know about the patient's hospital stay. For these reasons, having at least one post-discharge assessment by the hospital stroke team will offer an opportunity to post-discharge follow-up and modify care plan accordingly, answer if patients have any question, address any new issues, and prevent unwanted health outcome.

Deliverables:

- Recommendations to prepare individualized patient education material

- Recommendations to improve health literacy of patient education material

- A current CMMC booklet prepared with the used clinical scenario to offer a practical example of individualized patient education

- A booklet with revised words in compliance with CDC Plain Language guideline

- A list of non-complaint words in booklet according to CDC plain language guideline

- Written Capstone Paper

- Oral presentation

Results:

Since feedback from Mary Philbrick was incorporated into the recommendations and a booklet has been prepared as an example using a clinical scenario, CMMC should be able to implement individualized patient education immediately using their current booklet. It is important to note that since currently CMMC does not use any questionnaire to gather information about patient's need, contextual factors, barriers before patient education which is an integral part of individualized patient education; nurses need to ask patients these questions during education which will make the education session long. Thus nurses should be aware of that and plan accordingly.

Recommendations for the future have been prepared based on available best practice resources; they are time consuming and need supports and resources. However, CMMC can use these recommendations as a template whenever they are ready to implement evidence based individualized patient education.

The booklet has been reviewed to identify scopes to improve health literacy. It was found that the booklet is mostly compliant with health literacy guidelines including CDC Plain Language, PEMAT guideline, and Harvard guideline for assessing material for health literacy. Several words have been identified as non-compliant with CDC Plain Language guideline and one point has been found missing according to PEMAT guideline; appropriate recommendations have been prepared to address them. This capstone has definitely improved confidence on the booklet in terms of health literacy.

Limitations: Even though individualizing patient is not a very new topic, very few publications are available on this topic. Among them, most of the studies are on the efficiency of individualized patient education over generalized patient education. Very few articles describe the actual method of individualizing patient education. This capstone project was focused on method of individualizing education and has been prepared based on those available articles.

Lessons Learned:

Gathering information on this topic especially about the method was not easy. Also, as it was planned to contact researchers who have done studies and written articles on this topic, very few of them replied to email. Luckily, few researchers were very helpful and offered extensive supports. Lesson learned that it can be difficult to access right information and person; it needs patience and time which should be considered during project planning.

The project deviated from its proposal according the condition, barriers, and needs of CMMC nurses. Lesson learned from that it is important to stay flexible and make best use of resources and knowledge to have the best possible outcome.

References

Bushnell C, Duncan P, Lycan S, Condon C, Pastva A, Lutz B, Halladay J, Cummings D, Arnan M, Jones S, Sissine M, Coleman S, Johnson A, Gesell S, Mettam L, Freburger J, Barton-Percival B, Taylor K, Prvu-Bettger J, Lundy-Lamm G, Rosamond W. (2018). A person-centered approach to post-stroke care: The COMprehensive Post-Acute Stroke Services Model. *Journal of American Geriatircs Society, 66*(5). Retrieved from

https://onlinelibrary.wiley.com/doi/pdf/10.1111/jgs.15322

Duncan P, Abbott R, Rushing S, Johnson A, Condon C, Lycan S, Lutz B, Cummings D, Pastva A, D'Agostino R, Stafford J, Amoroso R, Jones S, Psioda M, Gesell S, Rosamond W, Prvu-Bettger J, Sissine M, Bonyton M, & Bushnell C. (2018). *Circulation: Cardiovascular Quality and Outcomes, 11*. Doi: 10.1161/CIRCOUTCOMES.117.004444

Kreuter M & Holt C. (2001). How do people process health information? Applications in an age of individualized communication. *Current Directions in Psychological Science, 10*(6), 206-209.

Oliver J, Kravitz R, Kaplan S, & Meyers F. (April 15, 2001). Individualized patient education and coaching to improve pain control among cancer outpatients. *Journal of Clinical Oncology, 9*(7), 2206-2212.

Rudd R. (No date). Guidelines for assessing materials. Retrieved from

https://cdn1.sph.harvard.edu/wp-content/uploads/sites/135/2012/09/resources_for_assessing_materials.pdf

Sewell M, Adebibe M, Jayakumar P, Jowett C, Kong K, Vemulapalli K, & Levack B. (2011). Use of the WHO surgical safety checklist in trauma and orthopedic patients. *International Orthopedic (SICOT), 35*, 897-901. Doi: 10.1007/s00264-010-1112-7

Recommendations to Individualize and Improve Health Literacy of Patient Education Material

Shoemaker S, Wolf M, & 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 Education and Counseling, 96*, 395-403. Doi:10.1016/j.pec.1014.05.027

Sullivan K & Katajamaki A. (September – October, 2009). Stroke education: Promising effects on the health beliefs of those at risk. Topics in Stroke Rehabilitation, 16(5), 377-388. Doi: 10.1310/tsr 1605-377

The Agency for Healthcare Research & Quality. (February, 2015). Health literacy universal precautions toolkit, 2nd edition. Retrieved from https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlittoolkit2-tool4.html

The AMA Foundation. (2010). Health literacy and patient safety: Help patients understand. Retrieved from https://www.youtube.com/watch?v=cGtTZ_vxjyA

The American Heart Association. (June 19, 2017). Healthcare providers should individualize patient education. Retrieved from https://newsroom.heart.org/news/healthcare-providers-should-individualize-patient-education

The Center for Disease Control & Prevention. (2007). Plain Language Thesaurus. Retrieved from https://www.orau.gov/hsc/HealthCommWorks/MessageMappingGuide/resources/CDC%20Plain%20Language%20Thesaurus%20for%20Health%20Communication.pdf

The Center for Disease Control & Prevention. (January 17, 2017). Stroke risk. Retrieved from https://www.cdc.gov/stroke/risk_factors.htm

Recommendations to Individualize and Improve Health Literacy of Patient Education Material

The Center for Disease Control & Prevention. (September 6, 2017). Stroke Facts. Retrieved from

https://www.cdc.gov/stroke/facts.htm

The Rural Health Information Hub. (No date). PRECEDE- PROCEED. Retrieved from

https://www.ruralhealthinfo.org/toolkits/health-promotion/2/program-models/precede-

proceed

Weiner S. (2004). Contextualizing medical decisions to individualize care. *Journal of Geriatric*

Internal Medicine, 19, 281-285.

Appendix A: Checklist

Checklist to keep track topics of patient counseling:

- Personal information- DNR, MPOA, important medical diagnosis, Important daily activities, emergency contact information
- Basic information about stroke
- Rehabilitation:
    - Movement and strength
    - Speech & language
    - Swallowing and nutrition
    - Memory and perception
    - Self-care and daily living (bathing, dressing, eating, toileting)
    - Setting short term and long term care plan
- Depression/ Post-stroke fatigue
- Addressing modifiable risk factors for stroke to prevent recurrence:
    - Blood pressure
    - High cholesterol
    - Diabetes
    - Smoking
    - Drinking
    - Atrial fibrillation
    - Obesity
    - Lack of exercise
    - Eating unhealthy
    - Taking medication:
        - Adherence and medication management
        - Financial management for medication
- Moving back to life:
    - Level of function
    - Transportation
    - Employment

- - Support group
  - Rebuilding intimacy
- Support for caregiver
- Resource directory:
  - <u>Provider directory- (name of organization, name of providers, phone number and address):</u>

1. Your primary care provider-
2. Your hospital stroke unit (M1, M2…)
3. Your pharmacy-
4. Your Outpatient Rehab unit-
5. Your social worker/ case manager-
6. Your Home Health Agency-

  - <u>Community resource directory:</u>

1. Area agency on aging- 8 Falcon Rd, Lewiston, ME 04240, Phone: 207-795-4010
2. Gateway Community Services- 501 Forest Ave, ME 04101, Phone: 207-536-1590
3. Senior Plus- 8 Falcon Rd, Lewiston, ME 04240, Phone: 1-800-427-1241
4. Catholic Charities- 15 Westminster St, Lewiston, ME 04240, Phone: 207-786-0925
5. Immigrant Resource Center of Maine- 265 Lisbon St, Lewiston, ME 04240. ME: 207-753-0061
6. Interim Healthcare respite care- 336 Center St, Auburn, ME, 04210. Phone: 207-783-6700

Appendix B: Non-compliant words according to CDC Plain Language in the booklet

- **Ability** - skill
- **Acute** – sudden start, short term, quick
- **Assess** – review, sum up, evaluate, to determine value
- **Assist** – help, aid
- **Contain** – have, keep together
- **Control** – manage, have power over, take care of
- **Contract** – arrange, agree, make smaller and shorter
- **Condition** – a medical problem, a disease, an illness
- **Disease** – illness, sickness
- **Determine –** figure out, decide, find out, test
- **Develop –** create, change, grow
- **Effect** – make, result
- **Effective** – works well, good, strong
- **Fatigue** – tired, weak feeling of the whole body, feeling tired all over
- **Hemoglobin A1c** – a test to show your blood sugar levels over the last 3 months
- **Intention** – goal, aim, desire, end
- **Interrupt** – stop, break
- **Maintain** – take care of, keep
- **Manage** – control, direct, be in charge of , take care of , watch
- **Modify** – change
- **Option** – choice, way
- **Permanent** – lasting, long term, forever
- **Portion –** piece, amount, part, serving
- **Prescription** – doctors orders, medicine, drug order
- **Prevent** – stop, keep from happening, forbid, keep, hinder
- **Prevention** – stop, bar, avoid
- **Provide** – give, offer, send, supply
- **Relieve** – ease, make better, soothe, rest
- **Recognize** – accept, know, see, find
- **Recover** – get better, feel better, heal
- **Respond** – answer
- **Reduce** – lower, cut, trim, dilute
- **Reinforce** – make stronger, brace, support
- **Require** – need, ask of
- **Retain** - keep

- **Risk** – chance
- **Symptom** – sign (of disease or sickness)
- **Stable** – ok, no change, constant, even, unchanging
- **Reinforce** – make stronger, brace, support
- **Severe** – strong, serious, harmful, dangerous, very bad
- **Schedule** – plan, planning a time to do something
- **Spasm** – sudden, strong muscle tightening, jerk, painful twist
- **Stress** – physical, mental, or emotional tension or strain
- **Temporary** – short, brief
- **Trigger** – cause, starts, something that can bring on symptoms of a disease
- **Warning sign** – signals to alert you something may be wrong
- **Witness** – see, note, observe

Appendix C: PEMAT Tool

Understandability

- The material makes its purpose completely evident
- The material does not include information or content that distracts from its purpose
- The material uses common, everyday language
- Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.
- The material use active voice
- Numbers appearing in the material are clear and easy to understand
- The material does not expect the user to perform calculations
- The material breaks or "chunks" information into short sections
- The material sections have informative headers
- The material presents information in a logical sequence
- The material provides a summary
- The material uses a visual cues (arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key point
- The material uses visual aids whenever they could make content more easily understood
- The material's visual aids reinforce rather than distract from the content
- The material's visual aids have clear titles or captions
- The material uses illustrations and photographs that are clear and uncluttered
- The material uses simple tables with short and clear row and column headings

Actionability

- The material clearly identifies at least one action the user can take
- The material addresses the user directly when describing actions
- The material breaks down any action into manageable, explicit steps
- The material provides a tangible tool (menu planners, checklist) whenever it could help the user take action
- The material provides simple instructions or examples of how to perform calculations
- The material uses visual aids whenever they could make it easier to act on the instructions
- The material explains how to use the charts, graphs, tables, or diagrams to take actions