Title: Creating Effective Patient Education Brochures to Encourage Early Diagnostic Testing for Oral Cancer

Abstract: Due to the progression of oral cancer, it is considered one of the most preventable, yet deadliest cancers in the United States. Studies show that early diagnosis drastically increases a patient’s five-year survival rate. Lehigh Valley Health Network (LVHN) hopes to address the infrequency of early oral cancer diagnosis by providing community oral cancer-screening sessions and by providing patient education materials at the critical time period between detection and diagnosis. When effectively written for a targeted audience, patient education brochures could bridge the gap between detection and diagnostic testing and increase the number of follow-up appointments scheduled through the network.

Introduction: On May 20th, 2014, LVHN’s Department of Dental Medicine hosted an oral cancer-screening day for members of the community with concerns related to oral cancer or suspicious lesions in the mouth, throat or lip region. The screening day was advertised in the LVHN magazine, Healthy You. Patients were required to call ahead to set up an appointment on the screening day.

The clinic saw 32 patients and conducted a visual intraoral/extraoral screening of the mouth, head and neck. The oral cancer exam is used to detect, but not diagnose, cancerous lesions. At the event, the clinic did not provide diagnostic testing such as biopsies or brush cytology. Patients spoke with a dentist to help identify risk factors and predispositions. Suspicious lesions were identified in six patients.

The standard of care for oral lesions is reevaluation of any changes in the condition after a two week time period. If changes are identified, the dentist will conduct one, or multiple diagnostic tests to determine malignancy. Suspicious lesions of the six patients were documented and the patients were referred to the clinic or other practices for diagnostic testing. Of the six patients with findings, none scheduled follow-up appointments through either of the two LVHN dental clinics (however they may have been seen by outside providers.)

Unfortunately, the Department was unable to schedule follow up appointments during the screening session because they did not have access to the scheduling database. They provided a list of resources and contacts so the patient could schedule a follow-up appointment on their own. They also provided background information and generic oral cancer pamphlets created by National Institute of Health, Oral Cancer Foundation and National Cancer Institute at the conclusion of the appointment.

The goal of the program was to provide better access to oral cancer screenings for at-risk patients. The next step the Department hopes to achieve is a high retention rate of patients that follow through with oral cancer diagnostic testing. The staffs of the clinics have identified a need for better patient education techniques in hopes of increasing follow-up examinations scheduled and ultimately for diagnosis and treatment planning to be completed at the clinic.

The deliverable includes a patient education pamphlet at appropriate reading level with information on the appropriate stage of the oral cancer screening process. Additional information will be provided to patients in oral cancer packets, a compilation of generic and LVHN oral cancer information covering all steps of oral cancer: detection through treatment. If proper patient education intervention is provided between the detection and diagnosis stage then early diagnosis can be achieved.

Methods: Literature based research was conducted to gather information on the prevalence rate, risk factors, symptoms, detection and diagnosis methods, treatment plans and follow-up care related to
oral cancer and cancer of the head and neck. An analysis of effective patient education strategies was conducted and literature review was used to determine whether or not patient education pamphlets could be used to improve some or all of the clinic goals. Existing brochures were analyzed to see where improvements could be made. Literature was reviewed on the chances of survival based on early detection and diagnosis of cancerous lesions.

**Results:**

**Early diagnosis of oral cancer**

The success of oral cancer treatment is measured by a five-year survival benchmark. Patients with small tumors have an 80% survival rate, where patients diagnosed with Stage IV cancer have a 30% survival rate. (Baykul 739) The survival rate of oral cancer has not improved in correlation with advancements in cancer treatment. Intervention in the detection and diagnostic stage is a promising, new attempt to reduce the mortality rate by encouraging patients to promptly seek diagnostic testing.

The majority of oral cancer cases are not detected until Stage II or III when the cancer has advanced to lymph nodes and organs other than the site of origin. “Late diagnosis results in more expensive, aggressive and disfiguring treatments, lower survival rates, lower function and lower quality of life among survivors.” (Baykul 739) Detection and diagnosis at Stage I could prevent complications in treatment.

Precancerous lesions are not often visually identifiable, however erythroplasia is the most common manifestation that indicates squamous cell carcinoma may arise in the future. (Baykul 738) It has been shown that physicians detect oral cancers sooner than dentists, which is linked to co-existing medical conditions. People with the associated oral cancer risk factors such as tobacco and alcohol use see primary care physicians more frequently. (Baykul 740) Significant delay can occur between detection and diagnosis when conducted by different health care providers. Most physicians can detect disease but are uncomfortable with diagnosing; while dentists more suitably conduct diagnostic tests. Proper patient education and access to resources at this stage could link increased detection of cancer and early diagnosis.

“Use of a cancer information leaflet had a significant effect in raising the long-term level of knowledge of oral cancer in the general public and also had a secondary effect on disease awareness in the locale.” (Baykul 739) Lack of public knowledge of the risk factors of oral cancer and detection and diagnostic options, contributes to a high prevalence rate of oral cancer. More than 75% of subjects in a research study were unable to identify the two main risk factors of oral cancer; tobacco and alcohol use. (Baykul 739) Oral cancer is considered preventable because the risk factors are social habits that can be avoided. Due to the apparent importance of early diagnosis, patient education pamphlets provided at the detection stage could improve awareness and ultimately promote early diagnostic testing.

**Writing an effective education pamphlet**

Research suggests that people remember information depending on how it is presented to them. People remember 10% of what they read, 20% of what they hear, 30% of what they see and 70% of what they see and hear. (Jacobson 14) A brochure can be used to combine reading and visual material and will enhance understanding of the information. The most essential information patients need to identify at the post-screening stage is their risk-level for the disease and the importance of diagnostic testing. The brochure provides a glimpse at what their future and treatment options may look like with a positive cancer diagnosis. The goal is to show that LVHN is going to help them through the process.

The format of a brochure can be modified depending on the patient’s age, race or literacy level. It is important to identify the target population. Allentown, PA and the surrounding areas are socially and economically diverse. The Allentown population is comprised of 42.8% Hispanics and
Latinos, and 12.5% African Americans. (Census Bureau) The majority of patients who utilize the resources at 17th and Chew street clinic are of these ethnicities. Of residents over the age of 25, 21.4% did not fully complete a high school education. (Census Bureau) The average adult reads three to five grade levels below the highest level of education completed. (Jacobson 5) The target population for an informational brochure to be distributed at an oral cancer screening is male, over the age of 40, primarily Hispanic, with an 8th grade reading level.

Characteristics of individuals with low literacy levels cause them to misread vital information in understanding when to schedule a follow up appointment. These individuals tend to take words literally, skip over unfamiliar words and rely heavily on visual cues. (Jacobson 8) Reading level depends on sentence length and vocabulary level. When using scientific or medical terminology, the vocabulary should include the most basic term for conditions and symptoms. Two or three syllable words are appropriate, while acronyms or abbreviations are inappropriate. (Jacobson 29) The brochure was edited to remove negative phrases, contractions, abbreviations and complex medical terminology.

Information should be clear and concise and use as few words as possible. In a brochure with limited space for text it is important to use pictures and graphics to display main points and to repeat main points often. (Jacobson 26) The prevalence rate and risk factors section allows patients to put their own lives in perspective after identifying with risk factors or predispositions. At the bottom of this section, graphics are used to indicate the risk factors. The LVHN symbol also appears multiple times throughout the brochure. The symbol is easily recognizable and patients will associate the information in the brochure with the health network.

Careful consideration was used when choosing images for a visual educational tool. The images reflect the age and culture of the patients at risk. (Jacobson 14) Above a quote indicating the level of support provided by the network is a Hispanic, elderly couple with a doctor. The cover image depicts the 17th and Chew Street clinic. The cover image determines whether or not a person will pursue the information inside the brochure. (Jacobson 37) Patients are familiar with the location and it reassures them that the hospital is a place where they can find care and support.

The brochure is intended for those who have suspicious lesions identified in the detection stage. Between the detection and diagnostic stage is a crucial time to deliver important health care information. The patient must schedule their own follow up appointment to have the appropriate diagnostic test completed and treatment plan prepared if needed. The brochure presents contact information so the patient can follow through procedures within the network.

Data:
The age distribution for patients who attended the LVHN oral cancer screening resembles a bell curve congruent with national statistics on the age distribution of oral cancer patients. 15 females and 16 males were seen at the event.

The success of oral cancer treatment is based on a five-year survival rate after treatment is completed. The most common region for cancer development is on the floor of the mouth. The floor of the mouth has the lowest survival rate when detected at Stage IV. Oropharynx region has the lowest overall survival rate, independent of the stage in which it is diagnosed. The average survival rate is 75.4% when diagnosed at Stage I and 39.6% when diagnosed at Stage IV. (American Cancer Society)
A total of 64% of oral cancer cases go undiagnosed until the cancer has progressed to an advanced stage. (Bethesda) Regional: Stage 2 or 3, indicates that the cancer has spread from the origin site to the lymph nodes.

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<thead>
<tr>
<th>Prevalence and Mortality Rate</th>
<th>Based on Gender</th>
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<tbody>
<tr>
<td>Males</td>
<td>Females</td>
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<tr>
<td>1 in 66 will develop oral cancer</td>
<td>1 in 148 will develop oral cancer</td>
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<tr>
<td>1 in 264 will die from cancer</td>
<td>1 in 546 will die from cancer</td>
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<tr>
<td>25% Mortality Rate</td>
<td>26.4% Mortality Rate</td>
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Males are twice as likely to develop oral cancer within a one-year time frame. (Bethesda) Females and males have relatively the same chance of survival.

<table>
<thead>
<tr>
<th>Prevalence of Risk Factors in Cancer Patients</th>
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<tr>
<td>Risk Factor</td>
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<tr>
<td>Tobacco Use</td>
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<tr>
<td>Over 55</td>
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<tr>
<td>Alcohol Use</td>
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<tr>
<td>Male</td>
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<td>Sun exposure</td>
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<td>HPV</td>
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Risk factors include social habits as well as inevitable risk factors such as being male or over the age of 55. Combination of risk factors increases chances of oral cancer exponentially. (Oral Cancer Foundation)
Discussion:

The goal of the brochure is to provide continual education and encourage patients to schedule follow-up appointments with the clinic. The importance of early diagnosis, specifically in oral cancer cases, could be difference between life and death. The period of time between detection and diagnosis is a critical window of opportunity to provide patient education. Using effectively made brochures for patient education is a solution to keep patients on track for their diagnosis and treatment plan. The clinic has a visual representation for patients to take home so they will remember to follow up with LVHN for the diagnosis step.

There are many cancer information resources such as National Institute of Health, Oral Cancer Foundation and National Cancer Institute. This information is very reputable and generalized, however a patient will relate more with a brochure created by the network rather than general cancer brochure. A patient wants to see that the hospital where they will receive care is dedicated to their treatment and has resources within the community for them to utilize. When preparing informational packets for cancer patients, outside brochures are useful for general information, however the goal of the dental clinic was to create their own pamphlets with the available network resources. The picture of the clinic on the front and the reoccurring symbol throughout the folds of the brochure hints to patients LVHN is their best care option. By creating a clear and effective brochure, patients will be encouraged to not only follow through with the diagnostic stage, but also use LVHN has their health care provider.

Future suggestions:

The brochure can be distributed at future oral cancer screenings. Data can be collected on the number of patients in attendance and number of follow-up appointments scheduled and attended. The data can be compared to the first oral cancer screening in which the brochure was not distributed. A follow up survey could be taken to determine if the LVHN brochure had an impact on the patient's decision to pursue their diagnosis and where they choose to do so.

Another way to effectively use the brochure and enhance patient understanding is to have an auditory and visual presentation. With patients who have suspicious lesions, it may be more effective if the health care provider briefly goes over the pamphlet with the patient before departure. A future study could be conducted on the best way to combine visual, auditory and literature-based information to increase the number of follow up appointments.

References:


