# USING VISUAL CONCEPT MAPPING TO COMMUNICATE MEDICATION INFORMATION TO PATIENTS WITH LOW HEALTH LITERACY; A PRELIMINARY STUDY

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**Abstract**. Visual concept maps, used in conjunction with verbal patient counseling, may be useful to communicate critical medication information, assist patients with remembering medication instructions, and thereby improve low literate patients' medication adherence and health outcomes. Numerous researchers have stressed the importance of rigorous pre-testing before implementing the use of a visual tool with patients. This exploratory study represents the first pre-test of medication concept maps with first-year pharmacy students. Three concept maps were pre-tested for two chronic disease states: diabetes and asthma. These disease states were selected because the link between low literacy and poor health outcomes has been well established in relationship to them. All three concept maps were interpreted correctly by a majority of students at a rate that exceeded the American National Standards Institute mandate of a minimum of 85%, thereby indicating that the visual concept maps have potential as a communication tool. Students' provided feedback that will be used to improve the concept maps in preparation for pre-testing them with an audience of low literate adults and then later with patients. (175 words)

## 1    Introduction

It is hypothesized that using visual concept maps will aid low-literate patients in understanding and remembering how to take their medications. Using a limited amount of words, the concept map can describe how and when to take medication(s) on a daily schedule. An individualized medication concept map, in conjunction with patient counseling, may be a tool that could be used to communicate critical medication information to low literate patients. The potential exists that an individualized medication concept map may increase patient medication adherence and consequently improve patient health.

## 2    Background

Low functional health literacy has been found to be an independent predictor of medication nonadherence, meaning that patients do not take their medications as prescribed thereby leading to poor health outcomes (Dimateo, 2004). Health literacy, often defined as the ability to read, understand, and act on health care information, entails the ability to perform basic reading and numeric tasks in the health care context including comprehending prescription labels, appointment slips, insurance forms, and other health-related information (Schillinger et al., 2003; Kirsch et al., 1993). An expanded model of health literacy was proposed by Zarcodoolas, Pleasant & Greer (2005) in which the concept refers to a "wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks, and increase quality of life" (p. 196). The prevalence of inadequate functional literacy has been well documented, and it is estimated that as many as 44 million people in the United States have only rudimentary literacy skills and another 50 million have marginal literacy skills (Kirsch et al., 1993; National Work Group on Literacy and Health, 1998; Youmans & Schillinger, 2003). Recently released preliminary results of the 2003 National Assessment of Adult Literacy indicate that the average quantitative literacy scores of adults increased only slightly between 1992 and 2003, while the average prose and document literacy did not change significantly (Kutner, Greenberg & Baer, 2005). Similar lack of change was found in the adult literacy and life skills study in canada (Raising the Score) in which 42% of the population was found to have literacy levels that are below those needed for success in today's society. Low literacy is prevalent worldwide. In year 2000, 20% of adults over 15 were illiterate, meaning "there were about 860 million illiterate adults in the world. . . . [and] over 100 million children have no access to school, and countless children, youth and adults who attend school or other education programmes fall short of the required level to be considered literate in today's complex world" (UNESCO). The percentage of the United Kingdom population with low literacy is similar to the U.S., closely followed by Canada, while the Netherlands and Sweden have recorded somewhat lower numbers (Houts et al., 2001). Although health literacy can affect all social classes, it more commonly affects elderly, low income, poor, and minority patients. Low literate patients with chronic physical and mental diseases have been found to be less likely to improve their health (Youmans & Schillinger, 2003).

People with low health literacy will have difficulty learning information from many written patient medical materials, including medication labels. There are many reasons why a patient may choose not to follow medication instructions (Dimateo, 2004; Hanson & Hartzema, 1995), but some patients do not understand how to take their medications because they are unable to read the instructions, or in the case of multiple medications, remember them (Youmans & Schillinger, 2003; Baker et al., 1996; Gazmararian, Williams, Peel & Baker, 2003; Williams, Baker, Parker, & Nurss, 1998). Research has demonstrated that patients with low health literacy have difficulty with basic medication instructions. One study found that of 2,659 hospital patients, most of whom had low health literacy, 42% gave incorrect explanations regarding taking medication on an empty stomach, 26% for when the next appointment is scheduled, and 60% had difficulty with a standard consent form (Williams et al., 1998). Low health literacy can impair communication about the risks and benefits of treatment options (Davis et al., 2002) which is especially critical in the management of chronic diseases because patients "typically must cope with complex treatment regimens, manage visits to multiple clinicians, monitor themselves for changes in health status, and initiate positive health behaviors" (Schillinger et al., 2003, p. 84). Patients with low literacy have more difficulty naming their medications and may hold health beliefs that can interfere with adherence (Schillinger et al., 2003).

Research has shown that visual aids can increase a patient's understanding of their medication regimen(s) (Ngoh & Shepherd, 1997). Visuals accompanied by oral instructions have increased patients' recall more than if they are given oral instructions alone (Houts et al., 2001). Sojourner and Wogalter (1998) provided evidence that information provided in a redundant form, using pictures and text, helps patients in recalling information because the formation of the message is encoded in multiple places in memory. With difficult reading materials, patients may take the information out of context, skip over words, and become easily tired and frustrated (Doak, Doak, & Meade, 2002). Dowse and Ehlers (1998) noted that patients preferred medical information sheets with pictures that illustrate the text. Pictures stimulate interest and add meaning to written text (Houts et al., 2001). Patients prefer attractive simple materials and instructional graphics can increase comprehension of medical information (Andrus & Roth, 2002). General benefits of using visuals are being able to cross age and language boundaries and convey information quickly without relying solely on verbal communications (Moriyama, Harnisch, & Matsubara, 1994).

The use of visual concept maps may have potential to enhance patients' understanding of medication regimen(s). Visual concept maps can incorporate meaningful pictograms to diagram a flow or hierarchy of ideas. As a graphic knowledge representation tool, a concept map diagrams key ideas in a topic area and demonstrates the relationships among them (Novak, 1998; Hill, 2004). They provide written, visual, and spatial information and this combination is more likely to be retrievable from memory than written information alone (Robinson, Robinson, & Katayama, 1999). An individualized concept map detailing a medication regimen may be a tool that could be used to communicate critical medication information to low literate patients. Concept maps, used in conjunction with verbal patient counseling and written medication instructions, may further patients' understanding of their medication regimens and therefore potentially improve their medication adherence and health outcomes. One possible advantage of a concept map is that it is a portable tool that patients can carry with them.

This study represents a preliminary exploration of the efficacy of using concept maps for communicating medication treatment information to low literate patients with chronic disease(s). According to the American Nationals Standards Institute, more than 85% of people should interpret a visual correctly for it to be considered effective (American National Standards Institute, 1991). Many pictograms have failed in transmitting a message successfully because they have not been well designed or appropriately tested (Sojourner & Wogalter, 1998; Moriyama, Harnisch, & Matsubara, 1994). Numerous researchers have stressed the importance of rigorous pre-testing before implementing the use of a visual tool with patients (Ngoh & Shepherd, 1997; Houts et al., 2001; Sojourner & Wogalter, 1998; Doak, Doak, & Meade, 2002). The purpose of this study is to pre-test visual concept maps with first-year pharmacy students to determine if they are able to interpret them correctly. These students were selected because they have not yet studied pharmacotherapy and therefore were roughly analogous to patients in their knowledge of the selected disease states, and were less influenced by their existing knowledge of asthma and diabetes medication regimens than students who are further advanced in the curriculum. Performing this pre-test is the first of several pre-tests planned for this research. The researcher will use the information garnered from this preliminary research project to improve the concept maps before advancing to the next stage of pre-testing with adults at a literacy center, and then eventually with patients.

## 3 Methods

Three concept maps were developed for two chronic disease states: diabetes and asthma. These disease states were selected because the link between low literacy and poor health outcomes has been well established in relationship to them (Gazmararian, Williams, Peel, & Baker, 2003; Berkman et al., 2004; Paasche-Orlow et al., 2005). Patients with these diseases need to master self-care techniques, know how to take appropriate action in crisis situations, and in the case of asthma differentiate when to take maintenance and rescue medications. The concept maps were created in Inspiration 7.0 software. Symbols used were either selected from those available in the software or they were found on the Internet through a Google image search. Images of medications were accessed via the Medmaster website that contains actual photographs of the medications. The image used to indicate inhaler use is one of 23 USP-DI pharmaceutical pictograms. The concept maps rely primarily on pictorial information including photographs of the actual medications, while written information was kept to a minimum. This deviates from typical concept map structure in that the use of linking words has been minimized in order to reduce reliance on written words. Another deviation is that these concept maps lack a hierarchical structure (Novak, 1998) because the intent is to diagram the process of taking medications throughout the day rather than to diagram the relative importance of concepts in relationship to each other. The concept maps have been reviewed by several clinical pharmacy faculty and found to be accurate in illustrating the respective medication regimens. These maps are meant to be used in conjunction with verbal patient counseling to improve patients' recall of medication instructions.

The concepts maps were formulated following suggestions for using visual illustrations found in a literature search. Briefly, these include designing simple, realistic pictures with limited content, using familiar objects and symbols, using caution in the use of abstract symbols, and using background space appropriately (Ngoh & Shepherd, 1997; Houts et al., 2001; Sojourner & Wogalter, 1998; Doak, Doak, & Meade, 2002; Moriyama, Harnisch, & Matsubara, 1994). Visual concept maps should be thoroughly pre-tested with the target audience, however, the idea of using concept maps in healthcare is preliminary and the researchers believes they should be first tested with a non-patient audience to determine if they will be interpreted correctly prior to pre-testing them with patients.

A research protocol was approved by the Virginia Commonwealth University Institutional Review Board (IRB) to pre-test the use of the template concept maps with a convenience sample of a class of first-year pharmacy students in Fall 2005. The efficacy of using concept maps for communicating medical information was determined by tracking whether students' were able to accurately interpret the medication regimen described pictorially on the concept map. The concept maps were described as illustrations in the pre-testing so as not to confuse the issue by discussing concept maps.

The pretest consisted of asking students about their interpretations and perceptions of three visual concept maps that illustrate medication regimens for diabetes (Figure One and Two) and asthma (Figure Three). The medication directions, or Sig, were deliberately omitted so that students would not be led in their interpretations. Students answered three questions for each concept map: 1) how they interpreted the directions for taking the medication(s), 2) whether they were confused by anything in the concept map, and 3) what they thought should be changed, added, or subtracted. Following these, students were asked whether they believed concept maps would be a helpful method in communicating medication information, to explain their reasons why, and to add any other comments they might have. Finally, students were asked if they were asthmatic or diabetic to determine how many students had detailed prior knowledge of the disease states and the relevant medications.

These questions were contained on a four-page interpretation form. No personal identifiers were collected and students were instructed not to write their name on the form. Following University Institutional Review Board requirements, an explanatory cover page was attached to the Interpretation Form that detailed the purpose of the study, a description of the study and student involvement, risks and discomforts, benefits, costs, alternatives, voluntary participation and withdrawal, and information regarding to whom questions should be directed.

This exercise was conducted in a pharmacy communications course in the first year of a Doctor of Pharmacy program at Virginia Commonwealth University. The class session was devoted to explaining the use of visual aids to communicate health information to patients. Class began with a 5-minute introduction regarding what pharmacists are currently doing to aid patients with low health literacy. Distribution of the Interpretation Form was accompanied by explanation of the reasons for the study and directions for completing the Interpretation Form. Students were instructed that their responses would not affect their grades in the course, that their participation was voluntary and

that they were able stop their participation at any time. Students took approximately 10 minutes to complete the form. After the forms were collected, class was resumed with a presentation devoted to the idea of using visuals to communicate medical information.

There were 106 first-year Doctor of Pharmacy students enrolled in the communications course in Fall 2005, and 86 students participated in the study. Students admitted to the Doctor of Pharmacy degree program at this university must have completed a minimum of 68 hours of prerequisite courses including biology, chemistry, physics, organic chemistry, mathematics, public speaking, and English. Demographic information collected by the dean's office indicated that fifty-five percent of the students had completed prior degrees, primarily in chemistry, biology, and biochemistry. Sixty-seven percent of the students were female and 33% male. The median age of the class was 24 years (range 19 – 39). Sixty-seven percent of the students were Caucasian, 18% Asian-American, 7.2% African-American, and 4.5% other. The latter category includes students who do not identify with the aforementioned categories and international students. Information collected by the course instructor indicated that approximately half of the students had some pharmacy work experience.

## 4    Results

The first concept map portrays the use of 1 tablet of Glucophage 500 mg to be taken twice a day with meals and 1 tablet of Ditropan XL 5 mg. to be taken at bedtime (Figure 1). Of the students participating, 83 (96.5%) correctly interpreted the medication instructions. One more came close but his/her description was not specific about which medication was to be taken at breakfast, dinner, and bedtime. However, students had several questions. For example, 34 students (39%) wanted to know about whether Glucophage should be taken before, during or after meals, another four (4.6%) were concerned about whether it should be taken at a certain time before consuming food, and two (2.3%) were unclear about whether Glucophage should be taken with or without food. Seven students (8%) were uncertain about how many tablets should be taken. Several were concerned about symbols they found confusing. Four (4.6%) felt that the sun symbol being the same at morning, noon, and evening was unclear, and the symbol for food was also unclear to one (1.1 %) student. One (1.1 %) student felt that the arrow from breakfast to lunch was confusing, and five (5.8%) indicated that including a lunch sign when no medication was to be taken during lunch was misleading. Four (4.6%) students asked about patients who work odd hours, and another wanted to know what would happen if a patient skips a meal. One (1.1%) felt that the illustration was too cluttered.
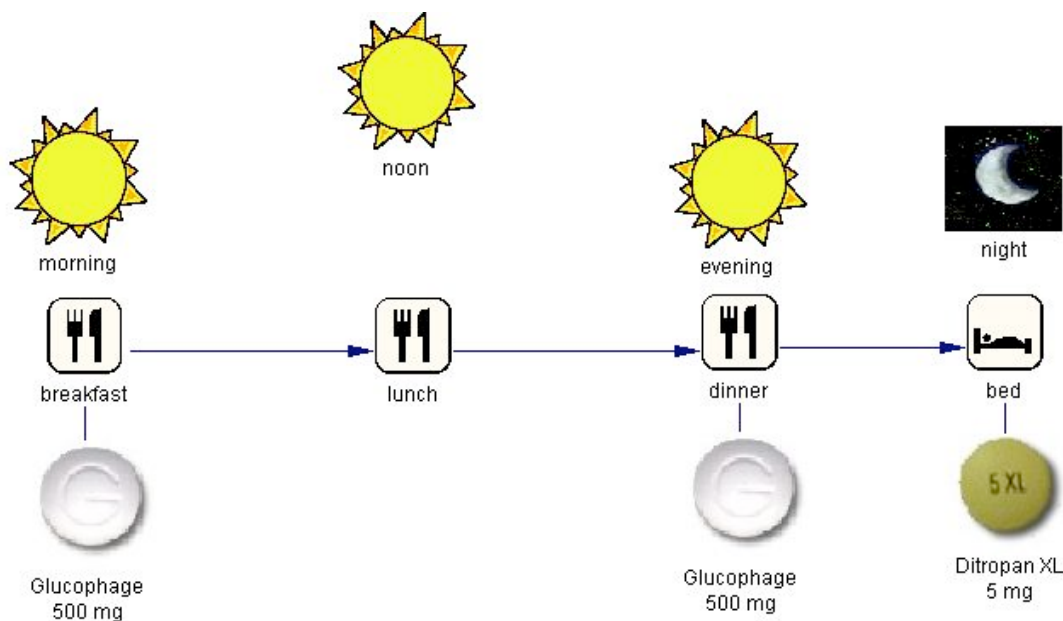


Figure One: Concept Map Illustrating the Use of Glucophage and Ditropan

Suggestions students had for improvement of Figure One included clarification for when the medications were to be taken. Twenty students (23%) suggested incorporation of an indication about whether Glucophage should be

taken before, during, or after a meal. Six (6.9%) students thought that lunch should be omitted from the picture and that the medicine names should be in a larger font size so the patient can see the medications better. Eight (9.3%) thought that the patient would need an indication of the number of tablets to be taken. Eight (9.3%) students wanted the illustration to indicate the number of tablets to be taken, and one suggested the use of color to help patients distinguish the medications. One (1.1%) wanted clarification regarded whether the medications were to be taken with or without food. Three (3.4%) students reiterated their concerns with the visual images for the sun, and felt they should be eliminated, while making the name of the drug and dosage stand out more. One (1.1%) felt that the size of the sun should be reduced because it was distracting. Six (6.9%) expressed the need for better images, and two suggested the addition of a few more words. Two students (2.2%) wanted a clear indication that the medication should be taken orally, and three (3.4%) wanted to see a clear differentiation made between morning and evening. One (1.1%) repeated his/her concern for the person working shifts who would need his/her medication regimen adjusted to suit his/her schedule. Thirty-seven (43%) made no comments.

Figure Two illustrates the use of insulin for treatment of diabetes. Eighty-four (97.6%) students correctly interpreted the concept map, while one misinterpreted the time of the dinner injection and one thought there should be three injections at bedtime which is not indicated in the illustration. When asked what, if anything, was confusing about the illustration, 30 students (34.8%) asked how much insulin should be injected, two (2.3%) wanted to know whether patients should test their sugar before or after injecting the insulin and one (1.1%) was concerned about how injections should be scheduled in relationship to snacks. Two (2.3%) thought that pictures of the sun were confusing and one (1.1%) suggested that pictures of lunch and bedtime should be eliminated since no injections were scheduled for those times. Forty-eight (55.8%) students made no comment. Thirty students (34.8%) had no suggestions for change, but 36 (41.8%) asked how much insulin should be injected, and four (4.6%) asked about where the medication should be injected, presumably referring to a body location. Two students (2.2%) suggested that the lunch and bedtime pictures should be removed, and three (3.4%) thought a clock should be used to indicate time. One (1.1%) thought the type was small and another (1.1%) felt that the text indicating that the medication should be taken "15 minutes before a meal" should be in bold. Again, one (1.1%) student stated his/her concern for how the medication protocol should be altered to accommodate a patient working night shifts.
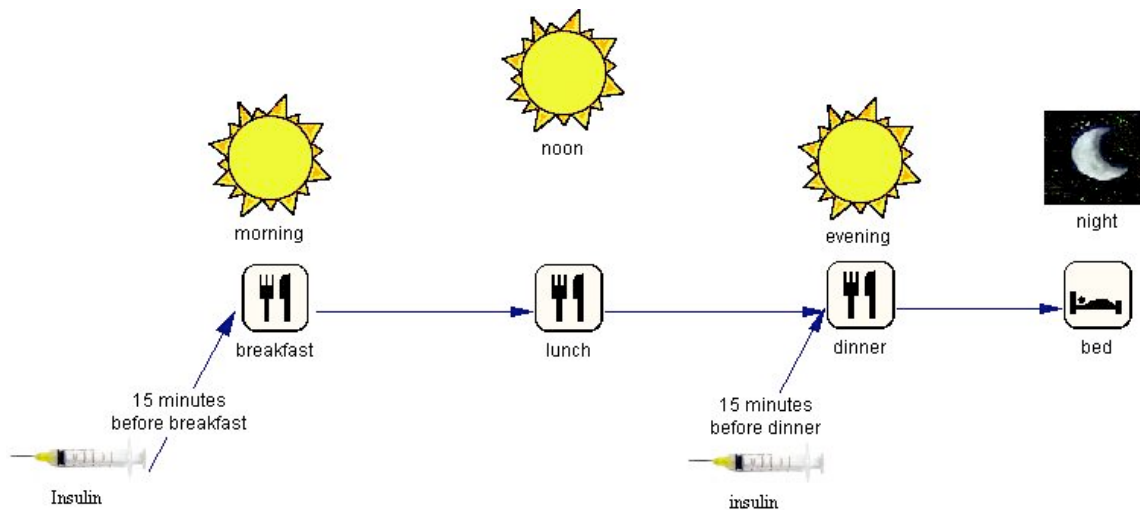


Figure Two: Concept Map Illustrating the Use of Insulin for Treatment of Diabetes

The third concept map illustrates the use of Albuterol as a rescue for treatment of asthma, in which a patient is to take two puffs with a one-minute interval between puffs, wait 20-minutes before repeating, and wait 20 minutes before repeating once more. If the treatment is not effective the patient is to call his/her physician before proceeding to the emergency room. Eighty-three students (96.5%) interpreted the concept map correctly while two (2.2%) were close but missed the necessity of using two puffs of Albuterol at each administration, and one (1.1%) stated simply that he/she was confused. Twenty-six (30.2%) students thought that stacking two pictograms one above the other was confusing, while another (1.1%) felt that that the USPDI pictogram looks like the patient is drinking the medication rather than inhaling medicated mist as the pictogram is intended to portray. Fourteen students (16.2%)

felt that the illustration contained too many pictures and arrows, and one (1.1%) thought that two arrows at each junction could be confusing. Fourteen students (16.2%) asked how many puffs of Albuterol should be taken. Three (3.4%) wanted to know why the doctor should be called prior to proceeding to the emergency room, and one (1.1%) asked about what to do if the doctor proves unavailable. Five students (5.8%) wanted to know how long a patient should wait after the third administration of Albuterol before calling the doctor. One (1.1%) asked whether relief would be instantaneous or would take 20 minutes. Twenty-nine students (33.7%) had no comment.

Figure Three was the most complex concept map, and when asked for suggestions for improvement, seven (8.1%) suggested the illustration should be simplified and contain less clutter and two (2.3%) students suggested that better pictures needed to be used. Four (4.6%) indicated that the part about calling the doctor and going to the emergency room needed clarification, and one (1.1%) suggested adding the emergency room's and doctor's phone numbers. The use of two puffs of Albuterol with a one-minute interval at each administration caused some concern. One student (1.1%) suggested using only one pictogram of inhaler use at each administration, and another (1.1%) wanted the two pictograms to be placed side by side with a plus sign to indicate two puffs, and still another (1.1%) suggested substituting the second pictogram with the words 'use two sprays.' Two students (2.3%) suggested the illustration should be clarified, two (2.3%) wanted more information to be added, two (2.3%) more thought the illustration should be more informative, and one (1.1%) thought the illustration should be larger. One student (1.1%) indicated that broken arrows instead of solid arrows should be used, and another (1.1%) believed that the addition of clock faces would be helpful. Finally, one student (1.1%) suggested that the word asthma instead of shortness of breath should be used. Thirty-five students (40.7%) made no suggestion.
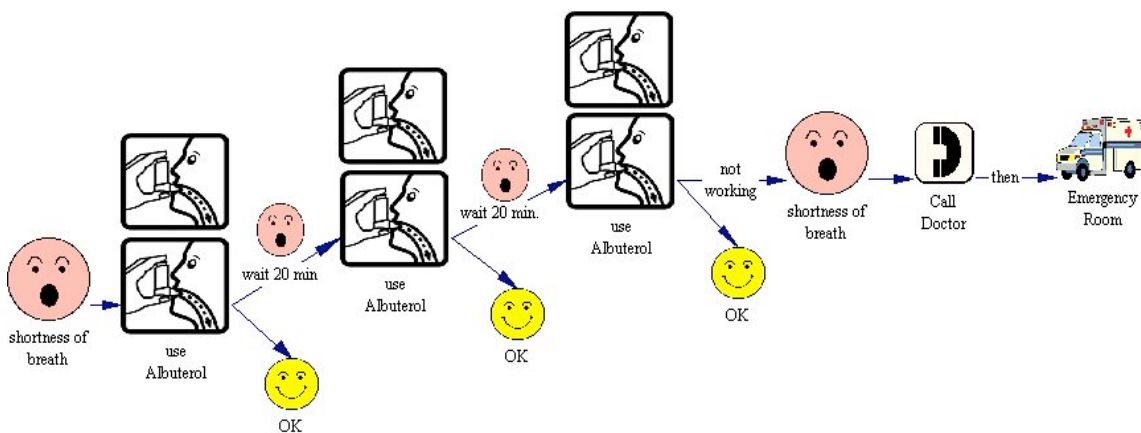


Figure Three: Concept Map Illustrating Rescue Medication Used to Treat Asthma

Few students made general comments about the use of concept maps for communicating medical information. Nine (10.4%) students felt that the visual concept maps were a good idea and that they would not be difficult to implement, while two (2.3%) suggested that the concept maps needed to be more descriptive and clear. For example, two (2.3%) students thought that the amount of medication and the times it should be taken needed to be included. Two (2.3%) felt that the diagrams could be made pocket-sized so that patients could carry the illustrations with them. Two (2.3%) suggested that graphic designs are good for people who cannot read, and another (1.1%) felt that visual concept maps provided patients with a 'play by play of what their day should be like' in relationship to their medication. At the same time, three (3.4%) students cautioned that the illustrations could cause more confusion especially if steps are missing or not labeled clearly. One (1.1%) suggested that the illustrations could add another layer of complexity. However, another (1.1%) student suggested that the visual concept maps could also be used with patients who read well because it offers an alternate way of understanding directions that some might find more convenient. Only one (1.1%) student had diabetes, while four (4.6%) had experience with asthma but only two (2.3%) had active cases.

## 5    Conclusions

All three concept maps were interpreted correctly by a majority of students at a rate that exceeded the American National Standards Institute's (1991) mandate of a minimum of 85%, thereby indicating that the visual concept

maps have potential as a communication tool. Nevertheless, a limitation of this study is that the pharmacy students selected for the first pre-test of the visual concept maps had reason to be interested in medications even if they have yet to learn in more detail about the two disease states of interest in this study. Given the mean age of the students it can be expected that they would have a high degree of visual literacy because of exposure to computers and video games. It appears that only a few had personal experience with the disease states, and thus most lacked detailed knowledge of the relevant medications. Some interesting responses were garnered from students that can be used to inform revisions of the visual concept maps before pre-testing them with a focus group of low literate adults and then with patients.

The variety of students' responses emphasize that there are many ways that individuals can interpret visual concept maps, or any pictorial image intended to communicate medication information. It appears that a few more words could be used to clarify the timing and dosage of medication administration, and larger font used for the limited number of words employed. Better symbols for indicating the time of day need to be found or created before further pre-testing. Students' responses indicate a need for parsimony in the concept maps as they appeared to dislike what they regarded as visual clutter. Students' concern for patients who work unusual hours verifies the researchers' original intention that the concept maps be tailored to individual patient's schedules and needs. Finally, the variety of students' interpretations and recommendations confirms what the literature indicates that visuals should not be used without being accompanied by verbal patient counseling performed by a knowledgeable health professional. The results of this study indicate that a visual concept map may have potential as a useful supplement to patient counseling and written medication instructions. Further pre-testing, incorporating the suggestions garnered in this study, will take place with adult students in a literacy program before proceeding to testing with low literate patients with the disease states of interest.

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