

HEALTHCARE LITERACY AND STANDARDIZED CHEMOTHERAPY EDUCATION: EFFECTS ON PATIENT OUTCOMES (AN INTEGRATIVE LITERATURE REVIEW)

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Abstract

Background: Health care is driven by its' outcomes. Nurses and other health care providers are always looking for ways to increase positive outcomes. Simply trying to provide patients with handouts and videos on their disease process may improve the outcomes for some patients but maybe not for all. The purpose of this article is to show in the literature that health care literacy is imperative for improving patient outcomes. When educating a patient with a potentially life-limiting illness timing can be crucial in reaching the patient. The materials for education and how they are presented can make an impact on whether or not a connection is made with that patient. The amount of time the educator has to spend with a newly diagnosed patient may also play a crucial role in defining a positive or negative outcome.

Methods: The first literature review explores the timing of basic education in newly diagnosed cancer patients and the media used. The second half of this article will review literature regarding health literacy. It will explore ways health care providers can reduce negative health outcomes due to low literacy levels.

Results: There needs to be more studies regarding how health literacy effects patient outcomes in oncology care.

Conclusions: Patients need more time with practitioners to develop a sense of trust. Patients receiving chemotherapy need to be educated and the studies show that no one way is superior than the other however, decreasing a patients' anxiety to open them up for learning is important as well as making sure you reach patients with the media that they learn best from. Health literacy has many areas in need of further research. "Clinicians are encouraged to develop interdisciplinary teams that include communication experts, marketing professionals, visual designers, health information technology experts, and librarians to deliver oral, visual, print and Internet-based information" (Egbert & Nanna, 2009).

Introduction

The time from diagnosis of cancer to the start of treatment can be a very anxious, fearful and confusing time for patients and their caregivers. They are given much information regarding their diagnosis and treatments and what is needed for them to care for themselves. Patients with inadequate health literacy are at risk for poorer outcomes and utilization of more services. "The ramifications for people with low to moderate healthcare literacy skills include the inability to assume positive self-management, higher

medical costs due to more medication and treatment errors, more frequent hospitalization, longer hospital stays, more visits to their healthcare provider, and a lack of necessary skills to obtain needed services (National Academy on an Aging Society)” (Egbert & Nanna, 2009). Education about chemotherapy is very important because chemotherapy comes with many side effects that can be managed if the patient is educated on what to do. “Providing concise, consistent, and individually relevant patient education is critical” (Schroeder, 2013). To date there has been limited research on how to effectively teach patients about chemotherapy and how to prevent and manage side effects. Providing patients with the tools and guidance to increase their healthcare literacy may lead to better outcomes and decreased healthcare costs.” The need to address this concern is noted in research findings indicating a relationship between patients with low health literacy and decreased levels of satisfaction with their primary care (Sheal et al., 2007) “(Egbert & Nanna, 2009).

Purpose and Significance

Managing side effects at the first sign of a problem can help to ward off larger problems that could potentially lead to a delay in treatment. “Interventions to reduce anxiety and/or depression prior to or during education sessions may have an impact on a patient’s ability to absorb information irrespective of the medium used” (Prouse, 2010). If patients are well educated and know what to do and when to call problems can be dealt with in timelier manner. “Participants who were informed, motivated and confident through developing their knowledge and health literacy skills became more actively involved in their care and were motivated to communicate their needs and concern to health professionals” (Edwards, Wood, Davis, & Edwards, 2012). The patient can feel better sooner and treatment can go on as planned. Educating the patient on symptom management and when to call the provider is the first step. Providing all patients with the same basic information in the same language is a good way to make sure all patients are receiving the same message. Offering this information to all patients in a DVD format that they can bring home and watch with family members prior to their chemotherapy education appointment allows them the opportunity to write down questions with the assistance of family that may not be able to be present at the education appointment. Having a DVD formatted to several languages increases patient knowledge and patients’ ability to carry out self-care. “The heavy reliance of the health service on written text, and the widespread use of medical terminology and jargon, had variously led people to miss or be late for appointments, to arrive unprepared for planned interventions, to struggle with leaflets or forms handed out “on the spot,” to fail to follow instructions or requests, and (compounded by any of these) to feel anxious and stressed before and during any conversations with clinicians” (Easton, Entwistle, & Williams, 2013). Allowing patients time to view chemotherapy basics at home will allow the nurse to be able to answer questions pertaining to the video and work the side effects the patients learned about into the chemotherapies that the patients are going to receive. “Some educational methods have been proven to decrease anxiety, which allows patients to retain more information. Many ways can be used to provide chemotherapy education, and no method has been proven to be significantly more effective than another” (Valenti, 2014). When speaking to health care literacy, in trying to reach a broader audience giving information in more than one format is imperative. If given only in print it is assumed that the patient can read written language. “In an effort to bridge the gap of understanding, many healthcare providers will offer patients printed health information in the form of brochures, articles, and/or books” (Egbert & Nanna, 2009).

Allowing patients to have some knowledge about chemotherapy in general before coming to their education session about their specific chemotherapy drugs may reduce their anxiety so they may retain specific instructions related to their drugs more readily. “Some of the challenges related to improving

communication with patients having low health literacy involve allowing nurses and other healthcare providers more time to interact with patients” (Egbert & Nanna, 2009).

Problem Statement

Does a standardized chemotherapy education video prior to specific chemotherapy drug education with an oncology nurse increase a patients’ knowledge of chemotherapy? Does low healthcare literacy provide for poorer outcomes? This study will look at the patients’ knowledge of chemotherapy prior to watching the chemotherapy basics DVD and their knowledge after watching the DVD. This article will also explore how health care literacy can affect the outcomes.

THEORETICAL FRAMEWORK

Introduction to Theory

Florence Nightingale envisioned nurses as educated women during a time when women were neither employed nor educated. It was Florence that began the history of the professional nurse. Through her vision and establishment of the first school of Nursing in London, modern nursing was born. Long before the era of evidence based practice as we know today was the error of theory base nursing. ”The theory era was a natural outgrowth of the research and graduate education eras” (Alligood & Tomey, 2010). With research there was theory and research without theory was just isolated information. “As our understanding of research and knowledge development increased, it soon became obvious that research without theory produced isolated information, and that it was research and theory together that produced nursing science (Batey, 1977; Fawcett, 1978; Hardy, 1978)“ (Alligood & Tomey, 2010).

Main Components to Theory

Betty Neuman’s Systems Model is composed of four Nursing paradigms; person, environment, health and nursing. The client system refers to the person which consists of five variables that are in interaction with the environment. The variables are physiological, psychological, sociocultural, developmental, and spiritual. The physiological variable is the body structure and function and the psychological variable is mental processes and interactions.

“The client system is a composite of five variables (physiological, psychological, sociocultural, developmental, and spiritual) in interaction with the environment. The physiological variable refers to body structure and function. The psychological variable refers to mental processes in interaction with the environment. The sociocultural variable refers to the effects and influences of social and cultural conditions. The developmental variable refers to age-related processes and activities. The spiritual variable refers to spiritual beliefs and influences (Neuman, 202c, p. 322; see also Neuman, 1982, 1989, 1995, 2002b)“ (Alligood & Tomey, 2010).

The Environment comprises the forces that may be internal or external that affect the client at any time. Developmental refers to the age the client is and the processes and activities for the client at that time. Sociocultural are the effects and influences that social and cultural conditions have on the client. Spiritual variable is the beliefs and influences that affect the client.

“Neuman considers her work a wellness model” (Alligood & Tomey, 2010). Health is the continuum from wellness to illness. “She views health as a continuum of wellness to illness that is dynamic in nature and is constantly changing” (Alligood & Tomey, 2010). Stressors that are tension pulling stimuli that may disrupt stability and cause either positive or negative outcomes. “Stressors are tension-producing stimuli that have the potential to disrupt system stability, leading to an outcome that may be positive or negative” (Alligood & Tomey, 2010). There are three types of interventions that can occur in response to stressors, primary, secondary and tertiary. “Interventions are purposeful actions to help the client retain, attain, or maintain system stability. They can occur before or after protective lines of defense and resistance are penetrated” (Alligood & Tomey, 2010). Primary prevention is used when there is a high risk of stress. “The purpose is to reduce the possibility of encounter with the stressor or to decrease the possibility of a reaction (Neuman, 1982, p.15; 2002c, p.323)” (Alligood & Tomey, 2010). Secondary prevention is initiated after symptoms have occurred. “The client’s internal and external resources are used to strengthen internal lines of resistance, reduce the reaction and increase resistance factors (Neuman, 1982, p.15; see also Neuman, 2002c, p.323)” (Alligood & Tomey, 2010). Tertiary prevention occurs after active treatment.” The goal is to maintain optimal wellness by preventing recurrence of reaction or regression. Tertiary prevention leads back in a circular fashion toward primary prevention” (Alligood & Tomey, 2010).

Nursing looks at the person holistically. “The Neuman System Model is a dynamic, open, systems approach to client care originally developed to provide a unifying focus for defining nursing problems and for understanding the client in interaction with the environment” (Alligood & Tomey, 2010).

This research proposal is primarily looking at patients’ knowledge of basic chemotherapy after diagnosis prior to standardized basic chemotherapy instruction and then their knowledge after standardized basic chemotherapy instruction. It is also taking into consideration a person’s health care literacy and how that effects the outcomes.

Support for Research Proposal

Neuman’s model has been used in education for both nurses and patients. The holistic perspective provides effective framework for education at all levels of nursing education. It has been used in clinical education as well as associate and baccalaureate degree education. “The model’s effectiveness as a framework for patient education has been demonstrated... The models inclusion of both client perception and nurse’s perception makes it particularly relevant for teaching across cultures” (Alligood & Tomey, 2010).

Using Neuman’s model educating the patients with some basic information is a primary prevention which should help to alleviate some of the stress for the patient. Using Neuman’s model educating the patient as an intervention for prevention of increased stress for the patient. This will lead to better outcomes for the patient for better wellness.

LITERATURE REVIEW

The review of this literature was done using database EBSCOhost. The databases used were CINAHL with full text, Academic Search Premier, Education Source, GreenFILE, HealthSource, MedLine and PsychArticles. Years searched were 2003-2016, chemotherapy education produced 76 results, which was decreased further but choosing linked full text articles were also obtained through Oncology Nursing Society, Clinical Journal of Oncology Nursing archives with the search term chemotherapy education. Based on literature found there are few actual current studies regarding standardized

education and most articles were based on literature review of several forms of education. Considering an increase in oral chemotherapies relevant, current and timely education that patients can have at their fingertips for their review is imperative.

Additional review of literature was done using EBSCO host. The databases used were CINAHL with full text, Academic Search Premier, Education Source, GreenFILE, HealthSource, MedLine and PsychArticles. The years searched were 2006-2016. Healthcare literacy produced 58 articles, literacy in healthcare produced 31 articles and literacy in healthcare and teaching produced two articles. The literature shows that there is a correlation between the level of healthcare literature and the outcomes. There is however, literature that also shows that the level of healthcare literature can be modifiable.

Qualitative Literature Review

Reviewing patient preferences for education is another way of finding out what works for the patient. In a qualitative thematic analysis, 40 cancer survivors were interviewed regarding their treatment plan, education, and survivorship care plans. The participants were consented as required by the facilities institutional review board. They were given an incentive of \$25 to a local health resource store, snacks and free parking. “Participants were asked specific questions about content areas, including identifying helpful and unhelpful information and areas needing improvement or expansion” (Marbach, 2011). The interviews with the focus groups were recorded and transcribed. The patient education binder was an essential component to patient care. Patients reported that when they felt overwhelmed they were able to refer back to their binder for information. “Information could be read at the patients’ 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, 2011). This study clearly shows that the best way to find out what your patient needs is to ask your patient. “High-level education and survivorship care cannot be ignored in any cancer care setting” (Marbach, 2011).

In a qualitative study of 81 patients and caregivers at the Mayo Clinic in Rochester Minnesota, they found the inclusion of an eleven-minute video entitled *Managing Chemotherapy Side Effects* to be beneficial to their clientele. There was no compensation to the participants of this study. “Qualitative data revealed a range of coping strategies in the areas of diet (e.g., smaller, more frequent meals; avoid certain foods), mouth care (e.g., soda solution for sore mouth, rinse mouth often), and medication options. Even those who began chemotherapy prior to taking the class reported that they found value in the class” (Fee-Schroeder, 2013). There were limitations to the study in that those in the class were motivated to learn. “The DVD helped provide consistent information during the class and covered the most common evidence-based side-effect management strategies related to chemotherapy treatment” (Fee-Schroeder, 2013). Using a format such as a video can also help to bridge the gap of low health literacy.

The last article of qualitative content reviewed had eight participants, all women, in the development of patient education for women with gynecologic cancers. This was conducted by interviews in person and also focus groups that were recorded and transcribed. There was Institutional Review Board approval. As a result of the interviews it was found that, “The women explained that the literature available to them in their oncologists’ offices did not meet their education needs and, in addition, it was given to them too late after their diagnosis” (Matzo, 2014). Sexual health and chemotherapy is often not routinely assessed. “HCPs have indicated that the reason sexual health is not routinely assessed is because (a) they believe the patient will bring it up if it is a concern; (b) the perception that people are “too sick” to be sexual (Caruso-Herman, 1989); (c) lack of their own comfort

with the topic...” (Matzo, 2014). Many survivors are not prepared for changes in their sex lives. “The women reported that they wished they had been better informed about what to expect regarding possible sexual health alterations, so that they could be more proactive in sexual health maintenance following their cancer treatments” (Matzo, 2014). More research is needed in the realm of appropriate education on sexual health for both male and female patients.

The outcomes expected of health literacy are that the patient should be able to reduce their overall health risks, improve their quality of life and make informed choices. To do so they must be of a literacy level that understands what is expected of them and what is needed to achieve such goals. “Lower health literacy has been associated with poor self-management [14, 15], limited involvement in health care consultations and decision making processes [16, 17], more emergency use [18] and more hospital admissions [19, 20]” (Edwards, Wood, Davies, Edwards, 2012). Identifying clients with low health literacy may be a challenge. “These factors include individuals’ lack of recognition of acknowledgement of their own low literacy [15, 17]; the shame and stigma associated with low literacy [18]; and low awareness among healthcare staff of potential difficulties with reading, writing or numeracy in the population of patients with no obvious language difficulties or cognitive impairments [19, 20]” (Easton, Entwistle, Williams, 2013). Clients may not know where to seek information or when to seek help based on their current knowledge base also contributing to poorer outcomes. Health professionals can be part of the solutions in improving these outcomes by recognizing that health literacy is a problem and screening for problems at every encounter with a client. “Supportive health professionals facilitated the development of health literacy by encouraging participants to engage with information before making a treatment choice” (Edwards, Wood, et. al; 2012).

Case Study

This case study on oral chemotherapy agents is from one patient interview. This one study brings up several important issues regarding education and patients being their own advocate. To summarize the scenario RC was prescribed an oral chemotherapy agent and was ill and missed her initial education appointment. She “fell through the cracks” so to speak and was never rescheduled. She received her oral chemotherapy drug which she began to take. She did receive education from the specialty pharmacy that filled the prescription. She was told by the specialty pharmacy of medications not to take while on the oral chemo. While on therapy she developed a urinary tract infection requiring antibiotics. The antibiotic prescribed was contraindicated. “However, if R.C. had not read the information provided by the specialty pharmacy, repeatedly sought information, and been an advocate for herself, she could have taken a contraindicated medication with her OAC, possibility leading to a significant increase in side effects and AEs - and even the need for hospitalization” (Spoelstra, 2015).

In a local outpatient cancer center, there was a case of a man in his early 60’s that exemplifies the impact low health care literacy plays in the care of the patient. This gentleman had a diagnosis of lung cancer and was often complaining of pain and tightness in his chest. Upon further questioning and exploration of the possible causes it was discovered that in using his inhalers he was using his maintenance inhaler as the rescue inhaler and the rescue inhaler as the maintenance. It was also discovered that he was taking the inhaler completely wrong placing the inhaler to his lips quickly depressing the inhaler twice and exhaling. Luckily, he was taking the inhalers wrong at that time because taking the maintenance inhaler as a rescue inhaler had he been using it correctly could have had dire consequences. After proper teaching and a thorough explanation it terms the patient could understand as to why he needed to take the inhalers with a 2-minute wait in between inhalations and

how to properly inhale the puff he finally was getting relief and the pain in his chest was beginning to resolve. The patient also did not want to take any medications that he did not understand what they were for. A thorough medication reconciliation was done and notes were written on the bottles so he could remember what the medications were for. This increased his compliance with taking his medications as prescribed. Also, a review of any pertinent side effects was completed. The patient was encouraged to always take the pharmacist counseling when he received any prescription as they would go over what the medication was and any side effects he needed to be aware of. This gentleman's compliance with his treatment regimen has increased and he feels more comfortable asking questions.

Another example of health literacy and distrust in the health care system happened at a senior center with a group of nurse practitioner students. Ms. C came in with a horrible rash on her arm. Upon further investigation, it was found that it took her a year to build up the courage to come in as she was embarrassed because of her living circumstances. She was living in a home with 40 other women. She had gone from a home with a family to an apartment to "this". She used to have a great job until she had an injury to her back. She had a tough childhood with parents that fought in front of her all the time. She had many psychosocial issues and was afraid people would look down on her for it. The students spent an hour with her and listened. They referred her with the help of the professor to a clinic to have her arm checked out. The clinic also had mental health as she was looking for a place where she could talk to someone. They also referred her to the senior center's resource person to assist her in getting set up with all the programs she would qualify for to help her get back on her feet as her living conditions were really starting to increase her stress and anxiety. Taking an hour to listen and letting the patient know she was heard may have helped restore Ms. C faith in the health care system enough for her to get the help that she needed.

Quantitative Study/Literature Review

In one quantitative study evaluating the addition of video-based education it was hypothesized that, "patients who watch the "Staying Well During Chemotherapy" video in addition to receiving written and verbal instructions are able to better recall side effects of treatment and demonstrate early reporting of treatment related side effects" (Kinnane, 2008). This Randomized control study used allocation sequence by computer for its 64 participants. Half of the group was assigned to one-hour education by the nurse only and the other half received a standardized video education of 10 minutes 30 seconds plus the one-hour education with the nurse. "The video was designed to assist patients to remember the most important information with regard to self-help advice concerning nausea and vomiting. Infection, anemia, and thrombocytopenia, mouth care, dietary and fluid intake and control and prevention of constipation and diarrhea" (Kinnane, 2008). Given that people have different styles of learning the inclusion of video teaching to standard forms of education may help to reinforce patient knowledge. "Chemotherapy patients in the study also indicated it would be of use to watch the video at other time points" (Kinnane, 2008).

Chemotherapy related side effects can be manageable if patients report them in time. Patients must be taught what side effects that need to be reported are. This study reviewed nine studies that compared teaching media such as written formats, diaries, DVD's and psycho-educational materials. "... Multimedia devices did not improve the recall of information; however, in addition to standard care, they can be a useful tool to improve the anxiety and depression that some patient with cancer experience prior to and during treatment of their disease" (Prouse, 2010). Education of the patient can be complex and multidimensional. "Interventions to reduce anxiety and/or depression prior to or during education

sessions may have an impact on a patient's ability to absorb information irrespective of the medium used" (Prouse, 2010). This review raises questions of how can education interventions be used to assist in decreasing a patients' anxiety to help them retain the information that is being taught to them.

Literature Review: Chemotherapy Education

The last three articles reviewed are all literature reviews looking at chemotherapy education. In *Videos as Supplemental Education Tools*, a patient's age, language barriers, health literacy, socioeconomic status and exposure to technology should be considered. "The three primary learning styles are auditory, kinesthetic and visual (Mitchell, 2007). Although a person typically favors one method over another, a multisensory approach involving the ears, hands and eyes is often the most effective" (Frentsos, 2015). Developing a program that may have verbal, written and visual instruction would be the best way to cover all of the bases for all learning styles. "Studies have shown that multimedia tools are an effective method for patient education, even among patients with lower literacy levels" (Wang et al., 2014). This approach coincides with the Healthy People 2020 goal of using information technology to improve health outcomes (Frentsos, 2015).

At the Dana Farber Cancer Institute, they have several satellite facilities. They formed a team of nurses to improve the quality of their teaching by developing a standardized approach to patient education across the different campuses. To track their progress, they looked at their patient satisfaction scores before their intervention and following their intervention. The pilot program ran for four months and included 53 patients. The work group initiated a checklist and calendar and an educational survey for patients after their third infusion. "Standardizing chemotherapy education processed can contribute to improved patient understanding and high patient and staff satisfaction" (Dalby, 2013).

In the final literature review article *Chemotherapy Education for Patients with Cancer: A Literature Review*, sixteen articles were reviewed for this article. The articles included patient education via audio and video recording, in-person class, on-on-on discussion, and telephone calls. The articles reviewed did not offer a best way to provide education. Many articles were older than the five-year limit that were reviewed. "Patients should be given the opportunity to ask questions before and after teaching occurs and throughout the treatment process. Healthcare providers should explain the importance of chemotherapy education" (Valenti, 2014).

Longitudinal Study

In a longitudinal study of 525 community-dwelling persons of advanced age, health care literacy was measured as well as financial literacy. The participants of the study did not have dementia and could read and write. The design of the study asked the participants not only health related questions but also numerical questions such as percentage and basic arithmetic. The study found that those already with higher health and financial literacy were better equipped to make healthcare and financial decisions. Those with lower healthcare and financial literacy were not equipped to make the same decisions. "These finding may suggest that improvements in literacy in older adults, specifically in high-risk older adults, may lead to better health and quality of life in later years through improved decision making" (James, Boyle, Bennett, & Bennett, 2012). The research also shows that even the older adults with lower health and financial literacy can learn and improve. "Furthermore, our results indicate that certain groups of older adults may benefit most from better health literacy, namely persons who are older, poorer, and have lower levels of cognitive function" (James, et. al; 2012).

RESEARCH DESIGN AND RECRUITMENT PLAN

An interventional study has been designed to examine the education of the patient from the nurse led patient education and from a standard chemotherapy basic video followed by a nurse led patient education to determine if it satisfies the patients need for knowledge prior to chemotherapy. Patients have always received a 30 minute to one-hour nurse led education session on a date prior to their chemotherapy to learn about the drugs they are to receive. The time for this teaching session has slowly increased as patients have seemed more anxious over the years. A DVD was developed to cover the basics of chemotherapy and will be given out during the patient's visit to a doctor when the patient is told she/he will be receiving chemotherapy. The patients will be instructed to watch this video prior to coming in to meet with their nurse for their chemotherapy education session. The patients that have only received education with the nurse will receive a questionnaire (Appendix A). The patients that receive the DVD will receive two questionnaires one to complete after watching the DVD and one to complete after the session with the nurse (Appendix B and C). "Intervention research is a methodology that holds great promise as a more effective way of testing interventions" (Grove, 2013).

A local community hospital outpatient cancer center will participate in this study. All the nurses in the unit have undergone the facilities Human subject training and will be in-serviced on the questionnaires and how to present them to the patients. A small focus group of nurses will be formed to review all of the questionnaires. This will be done on a volunteer basis.

At the end of the study all the questionnaires will be reviewed by the focus group of nurses. The nurses will be looking for the strengths and weaknesses of the teaching models as well as any comments and suggestions from the participants. A chart will be made of the scores for each of the questions on each of the questionnaires as well as a sampling of suggestions which can be brought to staff meetings and unit based councils for review and follow up for future plans and development of further teachings or updates on the current teaching models.

Recruitment Plan

The questionnaires will be given out over a time frame of four months from April 1st, 2016 until August 1st, 2016, for the non DVD group and August 2nd, 2016 until December 2nd, 2016 for the DVD group. The questionnaires will be handed out to all patients receiving chemotherapy education so this may include some patients who may be returning for additional treatment after several years off. Patients will be asked if they would like to participate in a quality improvement study to assist in shaping the education program for the facility. No patient names, medical record numbers or any other identifying information will be used. There will be informational posters to make patients aware of the study posted in the waiting rooms of the Physicians' offices and Infusion waiting room telling patients of the quality study to improve education for the patients. It will explain the questionnaire and ask for their participation (Appendix D).

Sample Size and Setting

This study will take place at a small community hospital outpatient oncology clinic in Lowell, Massachusetts. Over a four-month time frame there should be approximately 150 new patients for chemotherapy. All patients will be eligible to participate as long as they can answer the questions themselves or via an interpreter. It is expected that approximately eighty to one hundred patients will participate.

Informed Consent

Informed consent will be implied by completion of the survey. All measures to protect patient rights and privacy will be taken. No personal information will be entered either electronically or in writing for any of the surveys taken. If taken electronically in survey monkey the patient will be entering under a nurses' code not their own. Participation is completely voluntary. Surveys will have no identifying information to be tracked in any manner, all paper surveys will be put in locked shredder as a matter of trust.

HUMAN SUBJECT DATA COLLECTION AND ANALYSIS

Informed Consent

This study will be submitted to the hospital based Institutional Review Board (IRB) where the study will be conducted. This study will consist of surveys with no personal data collection. Informed consent will be implied by completion of the surveys. The survey is strictly voluntary. The context of the survey will be explained to the patient. All nurses recruiting study participants will have a thirty-minute in-service on the presentation of the survey. All participating nurses must have completed the required Human Subject training which is required every three years. The survey is to collect data to improve the education process for the current and future patient's. The nurses will be instructed to give the patient the information, remind them it is completely voluntary, answer any questions they may have and instruct the patients they may put the survey in the locked box on the reception desk. This allows for more complete anonymity for the patient.

Data Collection Procedures

The data for this study will be collected in the form of a survey (Appendices A, B, and C). For patients that are able to use a computer these may be completed in clinic on an iPad via a survey monkey. No identifying information is required to participate in the survey monkey. Patients that are not computer savvy may complete them on paper and the will be manually entered by one of the study investigators that holds the password for the survey monkey. All paper entries will then be placed in a locked shredding bin once they are entered into the computer. The code for entering the information into the survey monkey will only be held by the chief investigator, the lead nurse and the head of the oncology research department. These are the only three people that can enter information into the survey monkey. At the end of the allotted time of the study, the three identified participants that hold the password to the survey monkey will run the reports and then a meeting of all of all the study participants will meet to review the data.

The survey monkey will show the descriptive data relative to each question. The investigators will then take the information and decipher it to then put it in a format to disseminate it to the rest of the staff. For instance, 65% of the patients felt that they strongly agreed that they were prepared for the side effects of the risk of infection. For a better visualization to all staff, a bar graph may be a good visual to show each response to each question. With the information in hand further plans can be made on what the patients felt they did not receive good education about and also utilizing patient comments there may be some suggestions on improvement possibilities. Individual focus groups can be made to address low scoring education areas to find ways to reach our patients in areas that the scores were low.

The first surveys the patients fill out will be evaluating their knowledge of chemotherapy with only education from the nurse. This will be conducted with patients that have received chemotherapy education within the past six months prior to the initiation of the educational DVD. The second set of surveys will be evaluating patient knowledge after chemotherapy education with just a DVD on chemotherapy basics and the third followed by meeting with their nurse for more specific chemotherapy information. This will also be over a three-month time frame. Given that patients are becoming more technology savvy the face of education may need to take on a new face of its own. New trials using social media, webinars, and other forms of electronic communication may be necessary to reach our younger and more technology savvy patients. This population will represent the group that falls in a higher health literacy. Given one of the constraints to determining health literacy is the shortened amount of time a practitioner has to spend with a client, a client undergoing chemotherapy tends to form a relationship with their primary nurse. As nurses spend more time with the client they gather more information regarding the patients' health literacy. Nurses find out what the client understands and often tailors the teachings to that client. It may be a calendar with check off boxes for medication compliance for someone that has a difficult time remembering if they took their pills.

Conclusion

The literature out there about chemotherapy education defiantly points to one thing and that is that education is a must. "...The importance of patient education is stressed. The literature shows that patients want to learn as much as possible about their cancer, its treatment, and managing the side effects (Bakker et al., 1999)" (Valenti, 2014). The best education program is one that incorporates a multi-sensory approach so that all learners have a chance at learning. There needs to be more studies on education within social media and computerized means for the younger generation. "Despite the enormous implications of low health literacy, there remains a significant amount of confusion surrounding the concept and its implications for healthcare professionals" (Egbert & Nanna, 2009). The more time the initial nurse teaching the patient has to spend with the patient to put them at ease and not make them feel rushed the better. This will set the stage for those with a low health care literacy to feel that it is a safe place. Health literacy is a multidisciplinary approach. "On the Pathways model, health literacy develops along a trajectory towards a number of milestones that include a greater knowledge, improved self-management and participation in (informed and shared) decision making. One important feature of this model that it highlights health literacy as both a process and as an outcome" (Edwards et al., 2010).

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Appendix A

Prechemotherapy Education Survey

We are doing an evaluation of our educational process. Please fill this survey out to help us assess how we well we are teaching chemotherapy and its side effects.

1. I feel that my teaching session with my nurse prepared me for the following potential side effects of:
Answer: 1. strongly agree, 2 agree, 3 no opinion, 4 disagree 5 strongly disagree

HEALTHCARE LITERACY AND STANDARDIZED CHEMOTHERAPY EDUCATION

- a. Risk of infection? 1 2 3 4 5
 - b. Risk of Bleeding? 1 2 3 4 5
 - c. Mouth Sores? 1 2 3 4 5
 - d. Nausea and Vomiting? 1 2 3 4 5
 - e. Diarrhea or Constipation? 1 2 3 4 5
 - f. Changes in Taste, Appetite, and Weight? 1 2 3 4 5
 - g. Fertility/Sexual changes? 1 2 3 4 5
 - h. Fatigue? 1 2 3 4 5
 - i. Hair loss? 1 2 3 4 5
 - j. Neuropathy? 1 2 3 4 5
 - k. Emotional changes? 1 2 3 4 5
2. I feel that my teaching session with my nurse prepared me for what to expect the first day of treatment. 1 2 3 4 5
3. Did you look up information about your chemotherapy treatments before your teaching appointment?
YES NO
4. Please add any comments you think would be helpful as we work to improve how we teach our new patients (environment, lighting, teaching materials, etc.).

Appendix B

After watching the chemotherapy video, I feel that I understand the potential side effects and am ready to manage them if the situation arises.

Answer: 1 strongly agree, 2 agree, 3 no opinion, 4 disagree 5 strongly disagree

- a. Risk of infection? 1 2 3 4 5
- b. Risk of Bleeding? 1 2 3 4 5
- c. Mouth Sores? 1 2 3 4 5
- d. Nausea and Vomiting? 1 2 3 4 5

- e. Diarrhea or Constipation? 1 2 3 4 5
 - f. Changes in Taste, Appetite, and Weight? 1 2 3 4 5
 - g. Fertility/Sexual changes? 1 2 3 4 5
 - h. Fatigue? 1 2 3 4 5
 - i. Hair loss? 1 2 3 4 5
 - j. Neuropathy? 1 2 3 4 5
 - k. Emotional changes? 1 2 3 4 5
2. I feel that the DVD prepared me for what to expect the first day of treatment. 1 2 3 4 5
3. Did you look up information about your chemotherapy treatments before or after watching the DVD?
- YES NO**
4. Please add any comments you think would be helpful as we work to improve how we teach our new patients (environment, lighting, teaching materials, etc.).

Appendix C

We are doing an evaluation of our educational process. Please fill this survey out to help us assess how well we are teaching chemotherapy and its side effects.

1. I have watched the DVD on Chemotherapy Basics and have now met with my nurse. My nurse has prepared me for the following potential side effects of:

Answer: 1 strongly agree, 2 agree, 3 no opinion, 4 disagree 5 strongly disagree

- a. Risk of infection? 1 2 3 4 5
- b. Risk of Bleeding? 1 2 3 4 5
- c. Mouth Sores? 1 2 3 4 5
- d. Nausea and Vomiting? 1 2 3 4 5
- e. Diarrhea or Constipation? 1 2 3 4 5
- f. Changes in Taste, Appetite, and Weight? 1 2 3 4 5

- g. Fertility/Sexual changes? 1 2 3 4 5
 - h. Fatigue? 1 2 3 4 5
 - i. Hair loss? 1 2 3 4 5
 - j. Neuropathy? 1 2 3 4 5
 - k. Emotional changes? 1 2 3 4 5
2. I feel that my teaching session with my nurse prepared me for what to expect the first day of treatment. 1 2 3 4 5
3. I feel the DVD helped me obtain some understanding of chemotherapy so I wasn't so nervous coming in to meet my nurse today and it made it easier to listen to what the nurse was saying.
1 2 3 4 5
4. Did you look up information about your chemotherapy treatments before your teaching appointment?
YES NO
5. Please add any comments you think would be helpful as we work to improve how we teach our new patients (environment, lighting, teaching materials, etc.).

Appendix D

Chemotherapy Education Needs YOUR Help!

From April 1st 2016 until august 1st 2016

Your nurse may have a questionnaire regarding your education.

This is completely anonymous!

Your help is greatly appreciated!

Please, fill out a questionnaire so we can develop a better teaching program to help you and your loved ones.

Thank you!

Your nursing staff

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