Assessing the Impact Timing of Chemotherapy Education has on a Patient's Ability to Self-Manage Common Side Effects

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Deanna Anderson, Student

Dr. Sharon E. Lock, Advisor
Dedication

This project is dedicated to my two daughters. I hope I have set a good example and helped you see the options are limitless. Always follow your dreams and know that I am behind you, wherever your adventures in life may take you. You are both my word and I love you more than you will ever know.

To all of my cancer patients I have encountered, you have each affected me in a special way. I have learned much more from each of you than I could have ever taught you. Three exceptional ladies that had a large impact on me professionally and personally are cheering me on from up above. Mary, Patricia and Angie, thank you for teaching me how to embrace a moment, make memories and display compassion and humility to everyone I encounter. I will forever remember each of you and the grace you each exhibited during your illness.

My work family, for without them always displaying support and providing words of encouragement, this adventure would have been near impossible. Sheri, for always knowing when I needed a hug or a push telling me to keep going, there is light at the end of the tunnel, I thank you. And last but not least, the addition of two lifelong friends, Tiffany and Michael. Without your technical support ☺ and being my sounding block, I would not have been successful.
Acknowledgements

I would like to thank all of the faculty and staff that worked so diligently to help me be successful, particularly my advisor, Dr. Sharon Lock and our “class mom,” Betty Hayes. Without your help, I would not have survived this journey. Without the statistical knowledge of Amanda Wiggins, I would not have been successful. For my clinical mentor, Dr. Renato LaRocca, you have shown me how I want to embrace the art of practicing medicine by meeting each individual where they are, providing facts but supporting their wishes within their journey.

“Norton Healthcare Scholarship Recipient: This Doctor of Nursing Practice project and program of study was fully funded through the University of Kentucky College of Nursing and Norton Healthcare academic-practice partnership.”
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Abstract

Purpose

A new diagnosis of cancer will often cause an individual to feel overwhelmed, confused and anxious (Kessels, 2003). Many patients often experience anxiety not only related to their cancer diagnosis but also in regards to the plausible side effects of chemotherapy (Greene, Nail, Fieler, Dudgeon, & Jones, 1994; Williams & Schreier, 2004). The purpose of this paper is to evaluate the association between timing of education provided to newly diagnosed patients undergoing chemotherapy for breast cancer and number of self-manageable triage calls to the oncologist’s office.

Methods

A retrospective study design was conducted on newly diagnosed breast cancer patients from January 1, 2016 to December 31, 2016, undergoing chemotherapy in two NCI clinics. The inclusion criteria consisted of medical records of males and females 18 years of age and older with a new breast cancer diagnosis, completed at least two cycles of chemotherapy, English as the primary language spoken and written, received standard of care only (no research trial) and received education at the initial visit or within 2 weeks of the initial physician visit. A total of 59 records were included in the study. Thirty patients were educated on the same day (Group A) as their initial visits with the oncologist and 29 were educated within two weeks of their initial visit (Group B).

Results

The first objective determined if the nature of the call for Group A involved symptom management in the form of diarrhea < 24 hours, fever < 100.4 degrees Fahrenheit or
nausea/vomiting < 24 hours, within the first two cycles of chemotherapy. The number of triage calls that met the criteria was 30% for Group A and 21% for Group B.

The second objective compared the number of triage phone calls for Group A and Group B to determine if there was a variation contributable to timing of education. A chi-square test showed that there was no statistical significance between the two groups.

**Conclusion**

In conclusion, the results of this study did not show a substantial difference in the outcome based on when the patients and caregivers were educated. Additional research needs to be done to focus on other types of cancer and other factors that could influence patient self-management of common side effects of chemotherapy.
Assessing the Impact Timing of Chemotherapy Education has on a Patient's Ability to Self-Manage Common Side Effects

Introduction

At the end of 2016, there were approximately 1,685,210 new cases of cancer diagnosed and 595,690 cancer related deaths in the United States (American Cancer Society [ACS], 2016). Cancer is now the second leading cause of death in the United States and accounts for one out of every four deaths; it is second to heart disease (ACS, 2016).

Breast cancer has the highest expected occurrence rate for females at a frequency of 246,660 new cases per year according to the ACS published 2016 annual report; lung and bronchus cancers are the second highest for both men and women with an estimated incidence of 224,390 new cases annually (ACS, 2016). Brain and other nervous system cancers have one of the lowest expected occurrence rates at 23,770 new cases annually (ACS, 2016). New cases of male only breast cancer in 2017 thus far are 2,470 with 460 deaths. Male breast cancer is rare and the mean age of diagnosis is 60 to 70 years of age (National Cancer Institute, 2017).

A new diagnosis of cancer can cause an individual to feel overwhelmed or anxious and often be described as the worst fear a person possesses (Anderson, 2017; Kessels, 2003). Many patients often experience anxiety not only related to their cancer diagnosis but also in regards to the plausible effects of chemotherapy (ACS, 2016; Greene, Nail, Fieler, Dudgeon, & Jones, 1994; Williams & Schreier, 2004). The exhibited anxiety can cause a reduction in the amount of information retained by the patient and caregivers who may also be involved in the education process. Kessels (2003) stated patients should not be educated during a time of high anxiety because of the probability they will be unable to realistically listen and sustain what is being discussed. Thought needs to be given as to when the appropriate time would be to deliver
information and education regarding cancer treatment. The purpose of this paper is to evaluate the timing of education provided to newly diagnosed patients undergoing chemotherapy.

**Literature Review**

There is little known regarding the optimal time for chemotherapy education. A literature review was conducted using the search engines EBSCOhost, PubMed, CINAHL and Google Scholar. Key terms and phrases included in the search contained timing of education in new illnesses due to limited results specific to chemotherapy. Many studies have demonstrated the importance of educating patients prior to the first cycle of treatment but there has been no consensus as to the best way or what “prior to the first treatment” specifically means (Fee-Schroeder, Howell, Kokal, Bjornsen, Christensen, Hathaway, & Vickers, 2013; Garcia, 2014; Valenti, 2014). With cancer and chemotherapy already being a life changing event, it is the responsibility of care providers to determine when education should be implemented. Without evidence to rely on, a provider is left to speculate when the best time is to educate a patient. This decision should be made according to what affords the best outcome for the patient.

Rönnlund, Sundström, Sörman, and Nilsson (2013), conducted a cohort study with 721 participants who were categorized as high stressed or low stressed. The intent was to determine if high stress conditions impaired an individual’s memory and ability to retain information. Levels of perceived stress were measured by a researcher developed questionnaire and validated with the Perceived Stress Questionnaire. Participants with perceived higher stress rated their memory as worse over time than participants with perceived lower stress.

In 2017, Morgan, Cooper, Paul, Hammer, Conley, Levine, Miaskowski and Dunn, performed a longitudinal study that classified three groups of cancer patients based on their
personality traits. They were labeled as the “distressed”, “resilient” and “normative” groups. The distressed group had higher levels of depression and anxiety and lower scores in the personality domains of agreeableness and extroversion. The resilient group had lower levels of depression and anxiety and higher in agreeableness and extroversion. The normative group scored higher in depression and anxiety than the resilient group but their scores on the personality domains were between the distressed and resilient groups. The distressed group showed there was a negative effect on health outcomes due to depressive and anxiety exhibiting behavior. This group demonstrated a less efficient way to deal with adverse effects from chemotherapy than the groups who were scored as resilient or normative.

A further concern among providers is the delivery of education. Oncology nurses, educators, physicians and patient advocates from Mayo Clinic established a task force to develop an evidence based chemotherapy curriculum (Fee-Schroeder et al., 2013). The curriculum consisted of a nurse led education session that began with an 11 minute video on managing chemotherapy side effects followed by a question and answer session. There were 81 participants, 66 patients with cancer and 15 caregivers. This intervention demonstrated positive outcomes and found that many patients were able to appropriately self-manage side effects at home.

Valenti (2014) stated it was imperative for nurses and patients to develop a positive rapport. The importance of the relationship was to foster patient and caregiver comfort allowing the patient to ask questions and express themselves when they did not understand something. Garcia (2014) found that when education was provided in a quiet environment and prior to the first treatment, greater success was achieved. In addition, nurses who participated in a study to evaluate self-care agency of patients receiving outpatient chemotherapy believed that
understanding chemotherapy, the side effects that could occur and how to properly manage these adverse events, had shown a positive impact on patient success by not having to delay treatment (Kawasaki, Uchinuno, Arao, Kobayashi, & Otsuka, 2011). The ability to avoid delays in treatment has been found to promote better overall outcomes for the patient (Chavez-MacGregor, Clarke, Lichtensztajn & Giordano, 2016).

**Significance**

An initial office visit with the oncologist can be an overwhelming experience because patients frequently meet with multiple disciplines such as physical therapy, speech therapy and nurse navigator. While the main focus is the total care of the patient, each discipline has a specific agenda. A future appointment would give the patient time to process the information obtained from the physician visit and compile a list of questions concerning future aspects of their journey. Chemotherapy education is vital to the success of a patient completing their treatment plan. If adverse events begin to occur and early intervention can halt the progression, delay in treatment can be avoided. One way this could transpire is providing necessary information to the patient and caregivers at an appropriate time.
Theoretical Framework

A multitude of elements are significant in terms of totality but independence and self-sufficiency are two focal points essential to the fundamentality of life. Common knowledge recognizes that self-sufficiency is intrinsic and is an underlying element to the success of health. With this awareness, the self-care deficit nursing theory (SCDNT) cultivates the core of nursing (Orem, 2001; O’Shaughnessy, 2014).

Orem’s (2001) theory of self-care deficit focuses on a patient’s ability to care for themselves and take active responsibility for their health. Understanding chemotherapy, the effects that could occur and how to properly manage these adverse events, has shown a positive impact on a patient’s success (Kawasaki, Uchinuno, Arao, Kobayashi, & Otsuka, 2011). An empowered patient is more likely to be confident and trust themselves when making decisions. Being proactive can prevent adverse reactions from turning into serious complications requiring hospitalization.

Patients should feel empowered and truly integrated in their plan of care. Without input from the involved patient and family, expectations may be set higher than accomplishable or too low for the patient’s capability; both scenarios lead to failure of the provider’s role. True healing is maximizing a patient’s ability to perform ADL’s and assist when and where needed. This is not to be confused with providing guidance and education to patients and families with each interaction. Education will assist patients and their families to make appropriate, practical decisions permitting them the opportunity to participate in their plan of care.
**Objective**

The purpose of this study was to evaluate the timing of education provided to newly diagnosed patients undergoing chemotherapy at two Norton Cancer Institute (NCI) clinics that both provided care for patients with breast cancer. In both clinics chemotherapy education was provided by a nurse educator. One clinic (Group A) provided chemotherapy education at the initial visit with the oncologist and the other clinic (Group B) provided chemotherapy education at a later scheduled visit. Specific objectives included:

1. Determining the number and type of symptom based triage phone calls received within the first two cycles of chemotherapy for Groups A and B.
2. Comparing the number of triage phone calls for Group A and Group B to see if there was a variation contributable to timing of education.

Emphasis of this project was directed at whether the timing of chemotherapy education had an impact on a patient and their caregivers’ success at effectively self-managing common side effects such as diarrhea < 24 hours, fever < 100.4 degrees Fahrenheit or nausea/vomiting < 24 hours (ACS, 2016).
Method

A retrospective study design was conducted to evaluate the timing of providing education to newly diagnosed breast cancer patients undergoing chemotherapy in two NCI clinics. The inclusion criteria consisted of medical records of males and females 18 years of age and older with a new breast cancer diagnosis, completed at least two cycles of chemotherapy, English as the primary language spoken and written, received standard of care only (no research trial) and received education at the initial visit or within 2 weeks of the initial physician visit. Exclusion criteria was males and females less than 18 years of age, patients who were pregnant, incarcerated, had a developmental handicap, diagnosis of any cancer other than breast, English not primary language spoken and written, new diagnosis of cancer but participated in a research trial.

Since the information obtained for this project was collected at two NCI clinics, approval was obtained from NCI’s Chief Nursing Officer, Norton Healthcare Office of Research Administration (NHORA) and University of Kentucky Institutional Review Board (IRB). Because the project was a retrospective chart review, obtaining informed consent was not practical. Therefore, a waiver of informed consent was obtained.

A data request form with inclusion criteria was submitted to Norton Healthcare Information Technology department. The specified observation period requested was January 1, 2016 through December 31, 2016. A report was returned consisting of 184 medical records of patients seen during the time period. Each record was first reviewed to see if chemotherapy was received and if so, when the patient received education. If the patient did not receive chemotherapy, the record was excluded. The remaining records were further divided into two groups depending on when education was initiated. The first 30 records of patients who received education on the day they met with the oncologist were placed in Group A. The first 30 records
of patients who received education within 2 weeks after meeting with the oncologist were placed in Group B. Each of the sixty medical records used for data collection were first de-identified by using a crosswalk table and assigning a unique study number and letter to each chart. This unique number and letter were the only information used for the remainder of the project.

**Results**

**Objective 1.**

The first objective was to determine the type of triage calls received in the clinic within the first two cycles of chemotherapy. If the nature of the call involved symptom management in the form of diarrhea < 24 hours, fever < 100.4 or nausea/vomiting < 24 hours, the chart was used as part of the data collection. A total of 60 charts total were included; 30 patients were educated the same day as oncologist visit (group A) and 30 patients were educated within two weeks of the initial visit (group B).

Of the 30 patients’ educated on the same day as their oncologist visit (Group A), 21 patients, or 70%, either did not contact the office at all within the first two chemotherapy cycles or did not meet the symptom based criteria. Nine patients, or 30%, did contact the office within the first two cycles.

Of the 30 patients’ not educated same day as their oncologist visit (Group B), 24 patients, or 79%, either did not contact the office at all within the first two chemotherapy cycles or did not meet the symptom based criteria. Six patients, or 21%, did contact the office within the first two cycles.
Objective 2.

The second objective was to compare the number of triage phone calls for Group A and Group B to see if there was a variation contributable to timing of education. To test the association between timing of education and number of self-manageable symptom based triage calls received within the two specified groups, data were analyzed by a chi-square test using the SPSS program, version 23, by IBM. Results showed no statistically significant difference between timing of education and number of triage calls ($x^2 = 0.674$, df = 1, $p = .412$).

Of the nine patients in Group A that contacted the office within the first two cycles of chemotherapy, three called once, five called twice and one called three times. Of the six patients in Group B who contacted the office within the first two cycles of chemotherapy, four called once, one called twice and one called three times. Regardless of the group, all calls were self-manageable symptom based triage calls.

Discussion

A total of 184 charts from two NCI clinics were reviewed resulting in 60 patients meeting criteria, each with the diagnosis of breast cancer. Thirty of the patients received chemotherapy education on the same day at their initial oncologist visit, while 30 patients received chemotherapy education within two weeks of their initial oncologist visit.

The results demonstrated that out of the 30 patients educated on the same day as their oncologist appointment, 70% or 21 patients, either did not call the triage line or had a symptom or concern other than diarrhea < 24 hours, fever < 100.4 degrees Fahrenheit or nausea/vomiting < 24 hours. Of the 30 patients who received education within 2 weeks post oncologist visit, 79% ($n = 24$), either did not call the triage line or had a symptom or concern other than diarrhea < 24
hours, fever < 100.4 degrees Fahrenheit or nausea/vomiting < 24 hours. These results were not statistically significant and did not establish an obvious contrast as originally thought. One explanation for the findings may be that both groups received adequate education on how to properly self-manage expected side effects. In addition, patients may have looked up information on symptom management on the internet or had a family member or friend who provided guidance.

Due to the current void in research, it is difficult to establish if there is a right or wrong time to provide chemotherapy patient education. Kessel (2003) determined that patients are less receptive to retaining education if anxiety levels are elevated. Valenti (2014) and Garcia (2014) each demonstrated certain elements critical to a patient receiving maximum benefit from education. Two of the most common elements were establishing a reliable, trustworthy rapport with the nurse educator and receiving education prior to the first treatment. While a good rapport can be established and maintained at the initial office visit, specification as to what prior to the first treatment means is subjective.

Orem’s SCDNT encourages a provider to practice in a fashion that provides assistance to patients, in any stage of illness or affliction, to return back to their baseline as appropriate. The means to return a patient to their previous functional abilities is an oscillating process requiring reinforcement, flexibility, fortitude and encouragement. Support and accessibility must be maintained throughout the duration of the provider/patient relationship.

Patients need to feel empowered and truly integrated in their plan of care. Without input from the involved patient and family, expectations may be set higher than accomplishable or too low for the patient’s capability. True healing is maximizing a patient’s ability to perform ADL’s and assist when and where needed. This is not to be confused with providing guidance and
education to patients and families with each interaction. Education will assist patients and their families to make appropriate, practicable decisions permitting them opportunity to partake in their plan of care.

Limitations

There were several limitations in this study. Only individuals diagnosed with a specific type of solid tumor (breast cancer) were included in the data collection. The predominance of included individuals were female because breast cancer only accounts for <1% of all male cancers (National Cancer Institute, 2017).

Another limitation to be taken into consideration is the small sample size. When conducting research, the larger the sample size the more reliable the results. The small sample size can be attributed to the observation period of one year as well as only collecting from two clinics. Inclusion of other cancer diagnoses and additional clinics would provide superior results.

Implications for Practice

While these results do not show considerable difference, patient education and participation in the care plan are still vital to a successful outcome. In years prior, education had an unspoken but understood hierarchical premise; the healthcare provider furnished instructions and the patient was understood to be the object of care. With the changes in healthcare, it is imperative for patients to be active contributors. Insurance companies impact and often stipulate certain aspects of treatment generally placing more responsibility on patients and caregivers. However, awareness must be given to the fact that just because some patients and caregivers are capable and grasp the gist of education, many do not which results in unnecessary complications.

Each patient and caregiver is unique and must be looked at on an individual basis. Heightened states of anxiety are evident when diagnosed with a disease such as cancer. The
financial and mental burden placed on a newly diagnosed person may not be avoidable but how the patient is prepared and cared for by healthcare providers can be enhanced (Yan, Lijuan, Xingu, Mei, Huijuan & Yusheng, 2017).

**Conclusion**

In conclusion, the results of this study did not show a statistically significant difference in the outcome based on when the patients and caregivers were educated. Additional studies would need to be piloted including a range of not only solid tumor but liquid tumors as well. A multitude of factors would have to be considered focusing on the past and current mental health status of the individual and what type of support system they embody. While it is important to remember that a difference was not seen regarding time appropriate education within this study, each diagnosis, patient and social environment must be looked at on an individual basis and acted on accordingly.
Table 1

Cross Tabulation with Comparing Timing of Education and the Number of Self-manageable Symptom Based Triage Call

<table>
<thead>
<tr>
<th>Phoned office with self-manageable side effects</th>
<th>Educated day of oncologist visit (Group A)</th>
<th>Educated within two weeks of oncologist visit (Group B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>9 (30%)</td>
<td>6 (20.69%)</td>
</tr>
<tr>
<td>No</td>
<td>21 (70%)</td>
<td>23 (79.31%)</td>
</tr>
<tr>
<td>Total</td>
<td>30 (100%)</td>
<td>29 (100%)</td>
</tr>
</tbody>
</table>

$X^2 = 0.674, \ df = 1, \ p > .05$
References


