

Running head: COMPLEX ILLNESS SUPPORT

COMPLEX ILLNESS SUPPORT ALONGSIDE STANDARD ONCOLOGY CARE  
FOR PATIENTS WITH INCURABLE CANCER

Kimberly A. Bland

Nebraska Methodist College

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### Abstract

**Aim.** To evaluate the effect of Complex Illness Support alongside standard oncology care for patients with incurable cancer on symptom control, patient satisfaction with care, and chemotherapy utilization within 30 days of death.

**Design.** This was a descriptive study to evaluate the effect of Complex Illness Support alongside standard oncology care for patients with incurable cancer on symptom control and patient satisfaction with care. Additionally, the use of chemotherapy within 30 days of death was evaluated using inferential statistics.

**Method.** A convenience sample of consecutive patients with incurable cancer who presented through a lung cancer clinic in a Midwestern urban community hospital was utilized for this project. This was a descriptive study that examined symptom control, patient satisfaction with care, and chemotherapy use within 30 days of death. One patient satisfaction survey was used to evaluate patient satisfaction with Complex Illness Support care. Patients self-report of overall symptom burden (mild, moderate, severe) was assessed and documented at the first consultation visit and at the three month follow up visit. For those patients who died within the study period, the electronic medical record was reviewed to determine chemotherapy utilization within 30 days of the patient's death.

**Results.** Through the lung cancer clinic, 13 physicians referred 22 patients with terminal illness to Complex Illness Support for a total of 22 patient visits over a 5 month timeframe. Of the 18 patients seen, 10 have died (56%). Patients were highly symptomatic and a variety of interventions were used to support patients. Symptoms of

the two patients seen consistently remained stable from initial consultation to the three month follow up visit. Chemotherapy use within 30 days of death (two of the four patients received chemotherapy) was within national benchmark measures, and patients strongly endorsed satisfaction with the Complex Illness Support team.

**Conclusion.** Patients with incurable cancer frequently experience significant symptom burden and psychosocial distress. Complex Illness Support addresses many of these concerns. Patients and providers are accepting of and asking for outpatient Complex Illness Support. In this five month project, 56% of patients referred to this service died; this affirms the rationale and need for early supportive care intervention. To ensure high quality care and early access to supportive services, Complex Illness Support needs to be available to patients where they most often access oncology care – in the cancer center. Integration of Complex Illness Support as part of standard oncologic care would enhance patient care and satisfaction.

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### Complex Illness Support for Incurable Cancer Patients

There have been great advances in lung cancer treatment, but five-year survival remains dismal; average survival for those diagnosed with metastatic disease is less than 12 months (Jacobsen et al., 2011). Inherently, palliative care helps people with serious and life-limiting illness. The integration of palliative care early in the course of disease for patients with incurable cancer has been shown to provide benefit to patients and health systems with improved symptom control, decreased non-beneficial treatments, decreased hospitalizations, and increased quality of life for whatever time is remaining (Bruera & Hui, 2010; Ferrell et al., 2015; Ferris et al., 2009; Glare, 2013; Temel et al., 2010; Yoong et al., 2013). There is wide-availability of inpatient palliative care services, but this service is not provided in this study's outpatient cancer center, where most oncology patients receive their medical care.

### **Background**

Oncology patients have distress from the moment they are diagnosed (Hui & Bruera, 2013). With life-limiting disease, the patient and family are overwhelmed; life will never be the same. Symptom and financial burden typically increases throughout disease trajectory (Bruera & Yennurajalingam, 2012; Zucca et al., 2015). How will they know they are getting the care they deserve? Will their symptoms be well controlled? Will they understand what they are being told? How will their family communicate and adjust? Who will they talk to? How and where will they die? Every aspect of life is impacted. How can they have the best quality of life for the time remaining? Palliative medicine providers are trained to care for people with serious and life-limiting illness,

such as cancer. The focus of this specialty service is to provide relief from physical and emotional symptoms, with the goal of improving quality of life for the patient and family. Communication, continuity, and collaboration are key principles. Research suggests that palliative care is associated with improved patient outcomes, patient and family satisfaction, and possibly prolonged survival (Meier & Brawley, 2011; Temel et al., 2010). Early palliative care consultation is feasible and acceptable to patients (Jacobsen et al., 2011; Temel et al., 2007). Working in partnership with oncologists and other disciplines for symptom control, patients are empowered with knowledge and honest communication to make decisions based on their personal goals.

Most oncology patients do not have access to early palliative care when it would be most beneficial (Temel et al., 2010). There has been substantial growth of acute care palliative care services, but outpatient services are rare. A common misperception by providers and patients alike is that palliative care is an option only at end-of-life; this results in late referrals and reluctance to accept this service. For this reason, more acceptable alternative names for palliative care are being utilized (Bruera & Hui, 2010; Berry, Castellani, & Stuart, 2016) such as Complex Illness Support. Early integration of palliative care (herein referred to as Complex Illness Support) alongside standard oncology care for incurable cancer patients provides the most holistic care model to meet the needs of complex and seriously ill patients (Bruera & Yennurajalingam, 2012).

Advancing population age and the increasing burden of cancer (Jemal et al., 2009) on the health care system has stretched current models of care. Oncologists are charged with “curing” the patient, controlling symptoms, and managing family issues;

this can very challenging in the standard clinic setting where time is limited (Cherny & Castane, 2003). Many oncologists have difficulty discussing aggressive treatment and finding a way to alternatively discuss the option of limiting or stopping treatment. Clinician acceptance of palliative care integration is variable, related to misperceptions, experiences, and concerns (Le et al., 2014). An interdisciplinary team is essential for cancer care (Ferris et al., 2009) to allow oncologists to focus on cancer treatment (Yoong et al., 2013). Complex Illness Support needs to be available where patients receive care.

### **Significance of Problem**

The diagnosis of cancer is devastating. Most oncology patients are not in the hospital, and most are not actively dying. Patients with advanced cancer will experience symptoms related to disease, treatments, and psychosocial stressors. They have significant social, educational, and decision-making needs which are often not met with standard oncology treatment. Treatment is very complex and requires a well-coordinated multidisciplinary approach. Symptoms are frequently not addressed fully or in a timely manner, which adversely affects quality of life. Information that could help patients may not be shared with them (Spinks et al., 2014) and they do not know what or who to ask. As a result, patients often have not thought about their goals, quality of life, or care options with active treatment or at end-of-life.

Complex Illness Support providers are experts in helping patients live fully throughout treatment while planning for end-of-life (see Appendix A, Complex Illness Support Patient Brochure). Access should not be delayed until there are no further treatment options for the patient. This is unfair to the patient and family, and results in



lost quality time, increased symptom burden, and little time to adjust to and plan for end-of-life. Outpatient Complex Illness Support is currently not available in the study sites cancer center. Besides being a noticeable gap, lack of this valuable service may be detrimental to patients and families, causing needless suffering during the limited time they may have left. Early Complex Illness Support should be provided alongside standard oncology care, to provide continuity of care for patients with serious and life-limiting illness throughout their cancer journey.

### **Target Population**

The target population for Complex Illness Support was incurable cancer patients seen through a lung cancer clinic in a Midwestern urban community hospital. Approval was obtained from the clinical partner for use of this setting and population for this project (see Appendix B, Clinical Site Approval Letter). The Nebraska Methodist Hospital Institutional Review Board (IRB) chair determined that this study was a quality improvement project and approval by the Board was not required. Expedited IRB approval was obtained through Nebraska Methodist College, with waiver of consent.

### **Stakeholders**

Assessing community health needs and developing an appropriate plan of action to address identified needs is essential to maintaining and improving the health of a population. A community assessment was conducted, focusing on embedding Complex Illness Support into the existing lung cancer clinic, which is a part of a Midwestern urban community hospital. The assessment process included input from stakeholders representing the broad interests of patients (Shi & Singh, 2015) that were to be served

by Complex Illness Support in the lung cancer clinic, including hospital administration, physicians, lung cancer clinic staff, palliative care, supporting personnel, hospital infrastructure staff, and patients.

A meeting was held to share information with institutional stakeholders on Complex Illness Support providing outpatient services to incurable cancer patients. Stakeholder relationships are critical for input, conversations to discuss process, responding to questions, and to engage the multidisciplinary team (Ramchandran, Tribett, Dietrich, & Von Roenn, 2015). Initially providing services on Thursdays as an embedded clinic, consistent Complex Illness Support providers were in the lung cancer clinic weekly, interacting with providers and patients. Frequent and consistent communication changed the manner in which people viewed Complex Illness Support, and daily interactions with oncologists reflected Complex Illness Support dedication and knowledge to meet the needs of cancer patients across the continuum. Regular updates were provided to hospital administration. Collaboration with engaged stakeholders in the assessment, planning, implementation and evaluation of the services provided ultimately led to the success of the program.

### **Purpose Statement**

The purpose of this project was to evaluate the effect of Complex Illness Support alongside standard oncology care for patients with incurable cancer on symptom control, patient satisfaction with the Complex Illness Support care, and chemotherapy utilization within 30 days of death.

### **Clinical Question (PICO)**

What is the effect of Complex Illness Support alongside standard oncology care for incurable cancer patients on symptom control, patient satisfaction with care, and chemotherapy utilization within 30 days of death?

### **Intended Outcomes**

1. Symptoms will remain stable or improve (as per self-report, using mild, moderate and severe descriptors of overall symptoms) from initial consultation to the three month follow up visit.
2. Patients will verbalize satisfaction with care received by the Complex Illness Support team as demonstrated through use of a patient satisfaction survey tool completed at the three month follow up visit (see Appendix C, Patient Satisfaction Survey Tool).
3. Chemotherapy utilization within 30 days of death will be less for those patients utilizing Complex Illness Support than for those patients not utilizing Complex Illness Support (patients receiving standard oncology care alone), as monitored through review of the electronic medical record.

### **Organizational Assessment**

This Doctor of Nursing Practice (DNP) capstone project was performed in a Midwestern urban community hospital. The acute care hospital is a 250 bed Magnet recognized community teaching, research, and medical facility, serving the greater urban area. There is a large catchment area for oncology patients including local, outstate, and surrounding states. A fully staffed and experienced palliative care team currently offers inpatient services 24 hours a day, seven days a week. The providers for

Complex Illness Support are part of the inpatient palliative care team. Oncology providers in the outpatient setting are currently utilizing the inpatient palliative care team for hospitalized patients.

As a cancer specialty hospital, oncology-related health needs present in the community were assessed to determine whether and how this health system could address these needs. A 2015 community health needs assessment prepared for this hospital system (Professional Research Consultants, Inc., 2015) identified cancer care as an opportunity area for the community. Using cancer incidence and prevalence rates, morbidity and mortality data, patient and program satisfaction surveys, and direct community input, initiatives and programs were developed to meet cancer related needs in the community, with special focus on reducing the impact of cancer.

This community cancer center, accredited by the Commission on Cancer, is located in a free standing building connected to the main acute care hospital. Multidisciplinary expertise provides holistic oncology care, including numerous cancer specific clinics, such as the lung cancer clinic. Lung cancer is the leading cause of cancer death in this metro area (Professional Research Consultants, Inc. 2015) and in the United States, and the second most common cancer in both men and women (Centers for Disease Control and Prevention, 2016). The lung cancer clinic is well-established, and fully staffed by nurses and support personnel with processes in place for patients to be seen by appropriate providers during a one day visit. The typical patient for this clinic is Caucasian and 60 years of age or older. However, all races and ages are affected by lung cancer and may be seen at this clinic. For this health system, unadjusted one year

survival for non-small lung cancer stage III (19.53% of those diagnosed) and stage IV (21.09% of those diagnosed) is 49.4% and 26.5% respectively (Nebraska Tumor Registry, 2016). Unadjusted 5 year survival is 11.3% for stage III and 5.3% for stage IV non-small cell lung cancer (Nebraska Tumor Registry, 2016), with a national average of 11.2% and 2.7% respectively for combined years 2003-2006 (Centers for Disease Control and Prevention, 2016). During 2015, inpatient palliative care's fifth year, the internal database identified that 761 new patients and 3,938 follow up patients were seen. The lung cancer clinic and the palliative care team are both assets to the health system.

### **Review of the Literature**

Early palliative care has been shown to provide benefits in quality of life, mood, and health care utilization (Temel et al., 2010). Research suggests that in contrast to fears about palliative care hastening death, referral to palliative care earlier in the course of illness may have the potential to lengthen survival, particularly in patients with advanced non-small cell lung cancer.

### **Literature Search Strategy and Databases Used**

The work on this project started in March 2015. A systematic review of the literature was conducted using well-known research engines that include Cumulative Index to Nursing and Allied Health Literature Plus with full text database (CINAHL), PubMed database, and National Guideline Clearinghouse as the main sources. Parameters and search words included full text articles, English language, human research articles, adult patients, and journal articles published from 2005 to 2016. The main key words used independently and collectively were lung cancer, lung neoplasm,

quality of life, palliative care, early palliative care, and oncology (see Appendix D for literature search flow diagram). The systematic assessment of each article included identification of the following elements: purpose, hypothesis/research questions, theoretical framework, setting, sample, methods/design, conclusion, nursing implication, and findings. The initial findings, using the identified key words individually and collectively, revealed 81 articles. The final analysis revealed 38 articles which consisted of two qualitative studies, fourteen quantitative articles, five integrative literature reviews, six national guideline position statements, and eleven informational articles from content experts that served as key resources for validating information related to this capstone project.

### **Scope of Evidence**

A literature review of integration of oncology and palliative care by Hui et al. (2015) found substantial growth in this topic as compared to 2010, with outpatient palliative care discussed most often. A systematic review by Davis, Temel, Balboni, and Glare (2015) identified a number of advantages of early palliative care, including improved symptom control, improved quality of life, less aggressive care at end-of-life, increased completion of advanced directives, shorter and fewer hospitalizations, less caregiver burden, improved caregiver quality of life, a reduction in medical costs, and increased patient and family satisfaction. A pivotal study by Temel et al. (2010) found that patients with metastatic non-small cell lung cancer who received palliative care had better quality of life, were less likely to receive aggressive care at the end of their life, and had a longer median survival of 2.7 months than those who did not receive

palliative care. The authors stated there was “clinically meaningful improvements in quality of life and mood” (Temel, et al. 2010, p. 739) and concluded that given the current trends towards aggressive and costly care near the end-of-life, early introduction of palliative care may help to lessen non-beneficial and burdensome costs to the patient and to society (Temel et al., 2010).

A second large cluster-randomized study (Zimmerman et al., 2014) of early palliative care for patients with advanced lung cancer identified a significant improvement in quality of life and symptom control. A study by Ferrell et al. (2015) evaluated the effectiveness of integrated palliative care with all stages of non-small cell lung cancer, with findings that correlated with Zimmerman et al.’s study. To see full potential, palliative care must be understood and used appropriately for benefits to be realized, by clinicians, patients and legislators (Parikh, Kirch, Smith, & Temel, 2013). These studies contribute to the body of literature on the value of palliative care, clinically and economically, supporting the recommendation of integrated palliative care services alongside standard oncology care.

A number of studies demonstrate avoidable costs and stressors to patients and health systems. Delgado-Guay et al. (2015) evaluated the frequency of potentially avoidable emergency department visits in 200 advanced cancer patients who were receiving outpatient palliative care. The primary reason for visits was pain, with constipation being the second most common reason; 23% of visits were considered avoidable. Altered mental status, dyspnea, fever, and bleeding were reported in the unavoidable visit group. Pain and constipation are distressing and uncomfortable

avoidable symptoms that are best managed preventatively; pain is often directly related to constipation. While there is no way to know how many emergency department visits were avoided with use of early palliative care, this study identifies the importance of proactive communication and services provided by early palliative care (Delgado-Guay et al., 2015). In a study evaluating chemotherapy use at end-of-life, Greer et al. (2012) found that when palliative care was introduced shortly after diagnosis of metastatic non-small cell lung cancer, there was a longer interval between chemotherapy and death than in those patients treated with standard oncology care alone (64 days compared to 40 days); the authors also identified earlier use of hospice care by one week (Greer et al., 2012).

Scheffey et al. (2014) evaluated the effect of outpatient palliative care with advanced illness on eventual hospice utilization. Patients who had prior outpatient palliative care had statistically longer hospice length of stays than those without (24 days versus 15 days). Scheffey et al. suggest that outpatient palliative care provides the information and tools the patient and family need to consider and accept hospice earlier; if patients have a positive experience with palliative care with improvement in symptoms and quality of life, they may be motivated through trust to use hospice sooner (2014). In a study looking at quality of end-of-life care, Hui, Kim, Roquemore, Dev, Chrisholm, & Bruera (2014) report that outpatient palliative care with advanced cancer improved patient quality of life compared to late referral, with less aggressive care at end-of-life, fewer visits to the emergency department, fewer hospitalizations, and less use of the intensive care unit. These benefits cannot be provided by inpatient



palliative care consultation alone, when the patient is already hospitalized. An evaluation of Medicare expenditures reflects that 30% of annual spending is attributed to the 5% of patients at end-of-life (Bruera & Yennurajalingam, 2012; Medicare fact sheet, 2015). Research suggests that early palliative care in patients with advanced cancer can lower medical costs and improve end-of-life experiences.

Families are also affected by early support provided by palliative care. Patients with advanced cancer frequently receive aggressive care near end-of-life, including repeated hospitalizations and intensive care unit admissions, even though this may not be congruent to patient goals (Temel et al., 2010). According to research by Wright et al. (2016), avoidance of ICU admissions, earlier hospice use and death outside of acute care were associated with family perceptions of better end-of-life care. Deaths in the hospital setting have been related to family dissatisfaction, delayed family bereavement, and post-traumatic stress disorder.

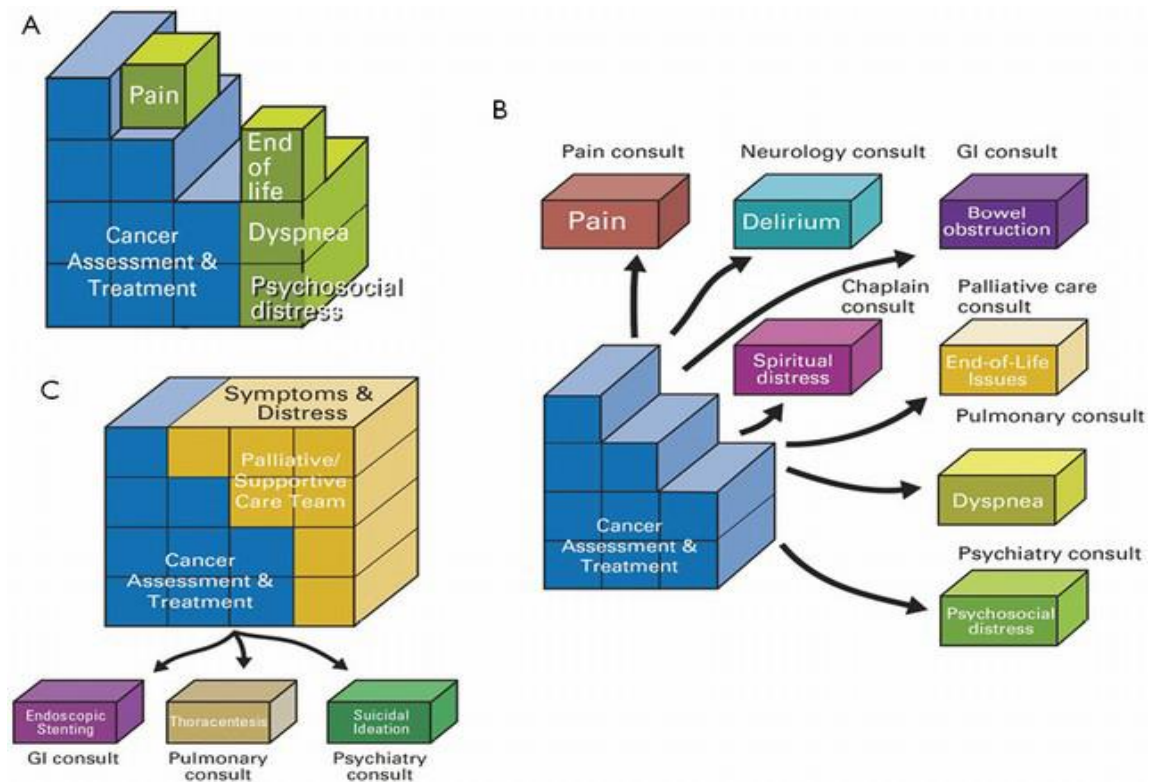
The use of palliative care has been included in national guidelines from the American Society of Clinical Oncology, the National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology for both non-small cell lung cancer and palliative care, the Commission on Cancer, the Center to Advance Palliative Care, the Institute of Medicine, the World Health Organization, and the European Society for Medical Oncology (Rabow, Dahlin, Calton, Bischoff, & Ritchie, 2015; Ramchandran et al., 2015). A policy forum, by the American Medical Association, argued that integrating early palliative care into oncology services for patients with advanced cancer would provide best practice to maximize quality and quantity of life while reducing symptoms and non-

beneficial care ( Zarrabi, Huo, & Meier, 2015). An official policy statement by the American Thoracic Society, American Association of Critical Care Nurses, American College of Chest Physicians, European Society for Intensive Care Medicine, and Society of Critical Care calls for consultation of palliative care when there is concern for potentially inappropriate treatments in intensive care units (Bosslet et al., 2015). Evidence suggests benefits of early palliative care; professional organizations have responded with guidelines recommending the use of palliative care alongside standard care in providing quality comprehensive care to those patients with serious and life-limiting illness.

### **Theoretical Framework**

The conceptual model for this Doctor of Nursing Practice (DNP) project was “Integration of palliative and supportive care in oncology”. This integrated care model was developed at MD Anderson in Texas by Dr. Eduardo Bruera and Dr. David Hui (2010); permission was obtained to use this model (see Appendix E, Approval to Use Conceptual Model). The authors recognize that cancer patients require complex and multidisciplinary interventions (see Figure 1). This model summarizes three oncology practice models to address supportive issues surrounding cancer patients. Figure 1A illustrates the oncologist managing cancer treatment and supportive needs. While the patient receives all care from one provider, it is impossible for one provider to do this for every patient. Figure 1B of the model illustrates the oncologist focus on cancer care, with referrals to numerous specialists to cover supportive needs; the result is fragmented, disconnected, and overlapping patient care. Figure 1C illustrates the

integrated-care approach between oncology and palliative care, with the oncologist focusing on primary management of the cancer and palliative care focusing on physical and psychosocial concerns. There is collaboration with other specialists as needed, such as pulmonary or interventional radiology, but the majority of supportive care is done through palliative care, thereby minimizing costs, visits, and interventions.



**Figure 1.** Conceptual model for integration of palliative and supportive care in oncology. Reprinted with permission from The University of Texas MD Anderson Cancer Center.

Under this model, all patients automatically receive comprehensive needs assessment and inter-professional management. Symptom concerns, prognosis, and advanced care planning are routinely discussed and re-visited with changes in health

status. Concurrently addressing both cancer treatment and symptom management through this integrated model will ensure the highest quality of care for cancer patients.

### **Methodology**

#### **Sample**

A convenience sample of consecutive patients with incurable cancer who presented through the lung cancer clinic was utilized for this project. Rationale for the non-randomized sampling technique was that it allowed the researcher to obtain basic data and trends for this study without the complications of using a randomized sample. Information obtained through convenience sampling limits the generalizations from this study. Through the lung cancer clinic, patients were readily available, and it was an efficient mechanism to access patients; data collection was facilitated in a relatively short time. In analysis of the last three years data from the lung cancer clinic, it was estimated that there were 50 patients annually with incurable cancer that would be appropriate for referral to Complex Illness Support.

#### **Setting**

The setting for this capstone project was a lung cancer clinic in a Midwestern urban community hospital. A 2016 program goal for this lung cancer clinic was to provide patient access to early palliative care. The intention was to provide Complex Illness Support to patients shortly after cancer diagnosis, to establish relationships, manage symptoms, provide education, and assist with decision-making and goal setting through continuity of care to improve quality of life. The lung cancer clinic is located in a community cancer center, which has availability of all services for routine care, including

supportive services. The cancer center is connected to the main acute care hospital, should further testing or inpatient care be required.

The lung cancer clinic is well-established, and fully staffed with a manager, nurses, data managers, and a secretary. This clinic sees patients who have lung lesions suspicious for cancer and those already diagnosed. Patients are seen on Thursdays in a dedicated office space which contains the infrastructure needed to support patients and provider encounters. Complex Illness Support was embedded into this clinic using existing space and staff. A multi-disciplinary tumor conference occurred over the lunch hour to review cases and to discuss recommended treatment and care of patients.

### **Project Design**

This was a descriptive study that examined symptom control and patient satisfaction with Complex Illness Support care in incurable cancer patients using Complex Illness Support alongside standard oncology care. Additionally, chemotherapy use within 30 days of death was evaluated using inferential statistics.

### **Psychometric Properties on Patient Satisfaction Survey**

There are currently no standardized tools or outcomes for palliative care. The instrument used for patient satisfaction with the Complex Illness Support team was modeled after a survey found on the Center to Advance Palliative Care website (2016); all information available on this site is open access for members to utilize. The purpose of this tool was to measure variables that could not directly be observed, audit the cares provided, and identify potential areas for improvement (Hearn & Higginson, 1997). This survey has not been validated, but was based off multiple palliative care satisfaction

surveys that have been utilized. All questions on this survey were important in this initial embedded project, to be certain that services provided were valuable to the patient; the intent of this survey was to measure what mattered. Results of this survey were used internally only in reporting results from this single site project. Face content and validity were used to select measures. This study provides psychometric evidence for the measures used, since this has not been investigated before. The survey was feasible for this program to use with low burden on patients to complete; results are not intended to be generalized.

#### **Data Collection and Procedures for Implementation**

A variety of existing (secondary) data were consulted to determine the appropriate population and setting to initiate outpatient Complex Illness Support. Sources include the Centers for Disease Control and Prevention, the National Cancer Institute, internal databases for the lung cancer clinic, palliative care and hospice, as well as numerous research articles related to oncology, lung cancer, palliative care, symptom management, and national guidelines (Benjamin, 2016). Focus groups with stakeholders provided valuable information about appropriate populations to reach and mechanisms of collaboration.

Primary data collection included date of Complex Illness consultation, referring provider, patient demographics, disease, disease characteristics, date of diagnosis, survival, palliative care provider, symptoms, number of visits with Complex Illness Support, and ICD-10 codes. This information is currently being manually collected for inpatient palliative care services, using an excel spreadsheet, and is reflective of the data

collected for and reported to the national palliative care data base. Additional data collected included patient satisfaction, symptom control, where patients are seen (clinic, home, assisted living, or hospital), emergency department visits, hospitalizations, intensive care unit use, hospice use, and chemotherapy use within 30 days of death. If patients declined consultation or were not referred to Complex Illness Support, lung cancer clinic nurses recorded the reason. For purposes of this capstone project, data collection tools included a patient survey for satisfaction with Complex Illness Support services, retrieval of documentation from the electronic medical record for symptom control, and if the patient died during the study period, retrieval of chemotherapy use within 30 days of death.

**Procedures and Implementation** (see Appendix F, Patient Flow Algorithm):

1. Patients seen through the lung cancer clinic were evaluated to determine if they have incurable cancer.
2. With approval from the oncologist, those patients identified were referred to Complex Illness Support for care alongside standard oncology care.
3. The lung cancer clinic nurse responsible for the patient used scripting to inform the patient about Complex Illness Support and co-pay required. If the patient agreed, the nurse then scheduled the patient's initial visit with Complex Illness Support, through the Complex Illness Support schedule book.
4. Patient appointments with Complex Illness Support were preferably arranged on a day when the patient was in the cancer center for another appointment.

5. For those patients who declined consultation or were not referred to Complex Illness Support care, the lung clinic nurse documented the reason that prevented this consultation; those patients received standard oncology care.
6. A dedicated provider of the Complex Illness Support team met with the patient and their family to establish a relationship and to discuss topics focusing on advance planning, decision-making, and symptom management. At this meeting, there was assessment of overall symptom burden as per patient self-report (rated as mild, moderate, or severe), with documentation in the provider's visit note as part of the electronic medical record.
7. The Complex Illness Support team forwarded documentation of the visit to the patient's oncologist and primary care provider directly after the visit, including any medications that may have been prescribed or referrals made.
8. Follow-up visits between the patient and Complex Illness Support was individualized based on patient need.
9. At the three month visit, there was assessment and documentation of overall symptom burden as per patient self-report (rated as mild, moderate, or severe), which was documented in the providers visit note in the electronic medical record. Patients were asked to complete a satisfaction survey related to Complex Illness Support. This was provided to the patient by the Complex Illness Support nursing staff, collected back, de-identified, and returned to the primary investigator.



10. Complex Illness Support continued to follow patients and schedule visits based on individual needs and requests. If a patient was admitted to the hospital, a member of the palliative care team followed up in this setting.
11. Patients utilizing Complex Illness Support through this project were tracked and if they died during the study period, the electronic medical record was reviewed for chemotherapy utilization within 30 days of death.

### **Ethical Considerations**

Responsibilities related to human subjects' protections for this project included awareness of ethical principles and established federal guidelines associated with human rights. This DNP student has completed courses in ethics training and the Collaborative Institutional Training Initiative (CITI) program course (see Appendix G, Principal Investigator CITI Training). Nebraska Methodist Hospital IRB Chair determined that this study was a quality improvement project, and approval by the Institutional Review Board was not required. Expedited Institutional Review Board (IRB) approval was obtained through Nebraska Methodist College, with waiver of consent.

Complex Illness Support was implemented in the outpatient lung cancer clinic starting October 6, 2017. Interventions delivered were within the scope of clinicians, and there was an established therapeutic patient relationship. The project team had ethical access to patient information, as well as clinical and organizational accountability for those affected by project activities. Data collected were existing and standard of care within oncology and Complex Illness Support. Risks associated with evaluation of data

were considered less than minimal, and patient surveys were de-identified prior to return to the primary investigator. Patients were treated with respect and dignity, and provided the opportunity to decline Complex Illness Support. There were no conflicts of interest identified.

Although the sampling process employed for the study was purposeful with a specific population in mind, there were no vulnerable populations involved and no threats to patients. Participants were informed of minimal to no risk related to the completion of the satisfaction survey. Benefits of obtaining the information from the survey were presented, as well as stressing that each individual had the option to choose whether or not to complete the anonymous survey.

The primary investigator facilitating this capstone project strictly adhered to the nursing discipline code of ethics and ethical principles as well as established federal guidelines surrounding participant involvement in the study. Patient privacy was maintained strictly following Health Insurance Portability Accountability Act (HIPAA) guidelines.

### **Data Analysis**

Descriptive statistics were used to assess symptom control and patient satisfaction with Complex Illness Support. Chemotherapy utilization within 30 days of death was analyzed with inferential statistics.

## Results

### Study Results

Of the 37 patients identified by the lung cancer clinic team as being appropriate for referral to Complex Illness Support, 22 were referred, of which 18 were seen; 10 of these patients died during the 5 month data collection period. The prevalent diagnosis was incurable solid tumor cancers, including lung, breast, pancreatic, mesothelioma, unknown primary, endometrial, cervical and prostate. One patient had acute myelogenous leukemia, one with myelodysplastic syndrome, and another with history of prostate cancer and terminal dementia. Patients without cancer involving the lungs were seen through the lung cancer clinic at referring physician request, in order to gain access for their patient to Complex Illness Support services.

### Sample Characteristics

**Age.** The sample ranged in age from 48-91 years. The mean age was 71.72 (SD=12.38). The median age was 75 years old.

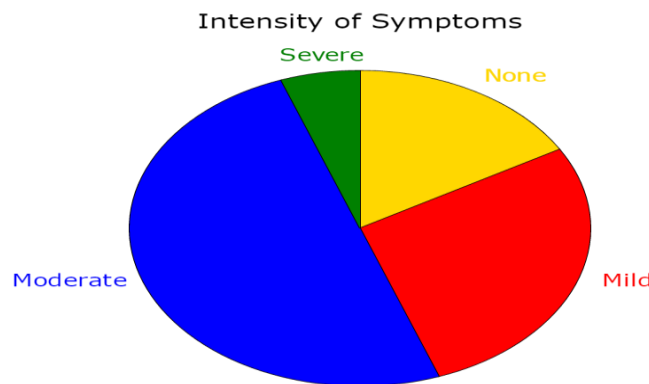
**Gender.** Females comprised the majority of the sample (n=16, 89%); Two males (11%) participated in the study.

**Ethnicity.** The majority of the participants identified their ethnicity as White (n=16, 89%); two individuals were Hispanic (11%).

Eighteen patients were seen by Complex Illness Support (13 were new patients, and five had previously been seen by the inpatient palliative care service and were therefore considered follow up visits) with a total of 22 patient visits. Treatment status at time of Complex Illness Support consultation identified that 14 participants were

currently receiving some form of cancer treatment (78%), three had stopped or refused treatment (17%), and one had not yet started treatment (5%). Of the 18 patients seen by Complex Illness Support, ten enrolled to hospice services (55%), nine of which died; one additional patient refused hospice services, but also died, which equates to an overall mortality of 55% during the 5 month project period. There were a total nine no show visits (7 patients). Three patients were later seen by Complex Illness Support. Two of the 4 patients not seen by Complex Illness Support died (50%).

Patients were highly symptomatic, with over 30 different symptoms described (See Appendix H). Complex Illness Support utilized a wide variety of interventions for symptom management and advance planning, individualized to what the patient identified as most important and what was most distressing to them (See Appendix I). Consultation with other supportive services was critical to manage patients, both emotionally and physically. Two of the 18 patients were seen regularly (11%), and both reported symptoms (as per self-report, using mild-moderate-severe as descriptors) were well managed and did not worsen from initial consultation to the three month visit.



**Figure 2.** Intensity of patient symptoms, per self-report, at initial Complex Illness Support Consultation.

Chemotherapy utilization within 30 days of death for patients using Complex Illness Support was evaluated and compared to national benchmarks as found in the literature. There were four patients (22%) receiving chemotherapy who subsequently died during this study period. The average number of days from the patient's last chemotherapy treatment to death was 39 days (range 14-58 days), with a median of 42 days. Two of these four patients (50%) received chemotherapy within 30 days of death.

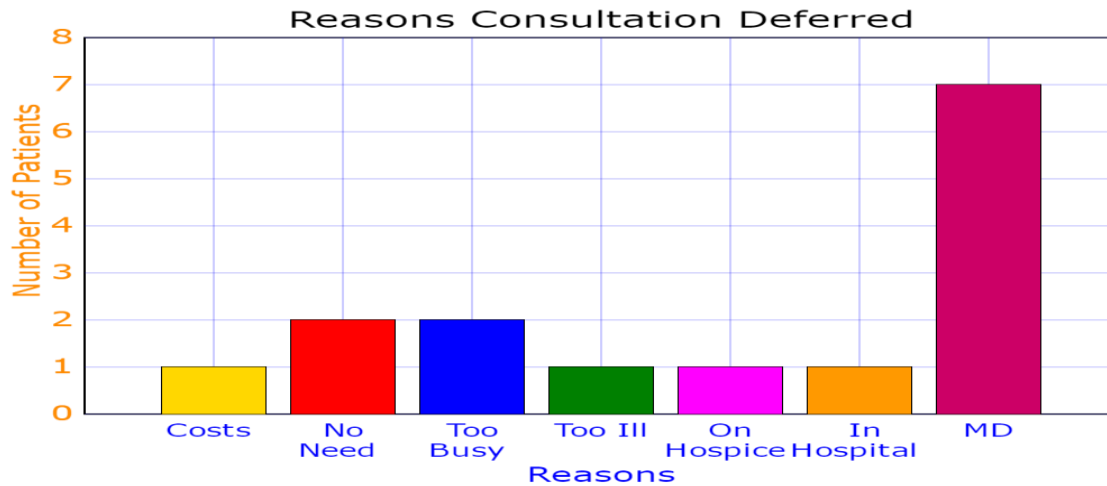
Patient satisfaction with the Complex Illness Support team was evaluated with the two patients followed consistently. Both patients strongly endorsed Complex Illness Support team as respectful and professional, able to talk about their goals and preferences for future care, helping them to feel more comfortable (emotionally and with symptom management), helping with coordination of care, and overall being strongly satisfied with the Complex Illness Support team.

## **Discussion**

### **Summary of results**

The population for this project involving a sampling of incurable patients reveals that, in general, symptom management and advance planning is an unmet need. Decisions about end-of-life care may be among the most complex made by patients and providers. Complex illness consultation provides support for poor-prognosis patients, as identified by symptom control, high patient satisfaction, and chemotherapy utilization within 30 days of death that is within national benchmark range of 9-50% of patients (Murillo & Koeller, 2006; Magarotto et al., 2011; Nappa, Lindqvist, Rasmussen, & Axelsson, 2011; Wright, Zhang, Keating, Weeks, & Prigerson., 2014).

A number of observations were made during this project in addition to the three outcomes measures evaluated. First and foremost, there is a large patient population and significant patient need to support the presence of Complex Illness Support in this cancer center; it would be in the best interest of the patient and the institution to fill this gap. National guidelines recommend that early conversations about end-of-life care occur soon after patients are diagnosed with a terminal illness (Mack et al., 2012). The clinical approach to patient management through Complex Illness Support is time intensive to assess and understand patient and family values, support systems, symptoms, education of their disease and prognosis, and to develop patient-centered goals. It was also time-intensive to set up infrastructure for this embedded consultation services, and frequent adjustments were required throughout this project to meet provider and patient needs. There were many physicians and patients who requested consultation, but because this was a pilot study with limited provider availability, many patients could not access this supportive service. While referral guidelines were in place for Complex Illness Support consultation, lack of oncologist support was the primary reason patients were not referred for consultation (Figure 3).



**Figure 3.** Reasons why patients did not receive Complex Illness Support consultation.

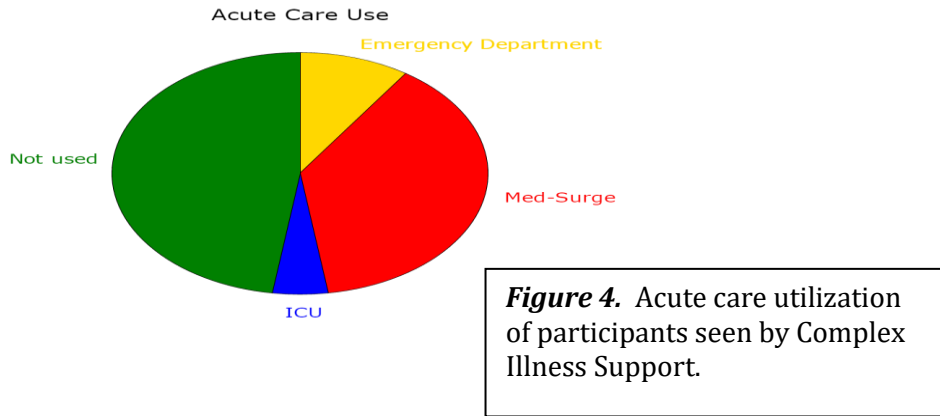
There were 7 patients referred to and scheduled for Complex Illness Support who did not show for appointments; reasons included scheduling errors, hospitalization, seeking a second opinion on treatment options, enrolling to hospice, and non-compliance. Three of these patients were later seen in consultation. With patient follow-up, scheduled appointments were cancelled due to hospitalization and patient's feeling too ill to come to the appointment.

Late referrals were common, when complex symptom management or difficult discussions were a priority. Complex Illness Support was well accepted by patients and providers, especially with these needs. Oncologists often wanted the Complex Illness Support team to take over management of medications and symptoms, but with limited availability, this was not possible. Interventions used by the Complex Illness Support team included medication adjustments, referral to support services, blood transfusions, and admission to home health care and hospice services. Code status and advance directives were discussed with every patient. Of the 18 seen, three had completed an

advance directive prior to consultation; five more completed an advance directive after consultation, and ten had no advance directive. This suggests that palliative care consultation may have provided the encouragement and guidance to complete advance directives for those who may have needed additional assistance (McDonald, du Manoir, Kevork, Le, & Zimmerman., 2017). Related to code status, three patients were a do not resuscitate prior to consultation, and after consultation, four more patients changed resuscitation status from full code to do not resuscitate.

Acute care was utilized by patients seen through Complex Illness Support. Of the 18 patients seen, two utilized the emergency department; one presented with weakness and pain, and was discharged back home. The other was on hospice and developed cough, vomiting and hallucinations, was discharged back to hospice. Eight patients were admitted to the hospital for a variety of reasons including cholecystectomy, syncope, pulmonary emboli, new atrial fibrillation, symptomatic malignant pleural effusion weakness, and symptomatic anemia; length of stay ranged from 1- 13 days. One patient with sepsis utilized the intensive care unit. Many prior conversations had occurred related to code status and goals of care. Temporarily on the ventilator, this patient was discharged to hospice house and died two days later.





**Figure 4.** Acute care utilization of participants seen by Complex Illness Support.

Comparison of acute care utilization (emergency department, hospitalization on med-surge unit, and intensive care) to the literature showed project rates on the positive end of comparison benchmarks. No patients in this project group died in acute care, compared to literature reporting 28.6% acute care deaths (Stuver et al., 2016). Hospice admission was 94% of patients compared to benchmark of 47-59.9% (Abramowski & Astarita, 2017; Stuver et al., 2016) and hospice days averaged 20.2, compared to benchmark of 4-19.7 days (Von Roenn & Temel, 2011; Abramowski & Astarita, 2017).

**Clinical Implications and Impact on Practice**

The healthcare reform environment is creating new opportunities for palliative care expansion. Organizations are in a state of transition living in both payment worlds, looking for strategies to impact quality and cost for their most complex patients. This creates a good climate to take a more strategic, proactive approach to match palliative care services with organizational needs. Few would be opposed to the alleviation of suffering and good end-of-life care. Clearly, providers have a personal stake in

developing a care system that meets the needs of patients, families, and friends. Good intentions, unfortunately, are not enough.

With the diversity and complexity of patient illness, the health care system must be adaptable. Complex Illness Support combines pain and symptom management, goal setting, family caregiver support, and practical and social support (Center to Advance Palliative Care, 2016). Current evidence demonstrates that Complex Illness Support is associated with improved patient outcomes, patient and family satisfaction, and at times, prolonged survival (Meier & Brawley, 2011). With an increasingly aging population and growth in the complexity of population health, community-based Complex Illness Support is a model of healthcare delivery which emphasizes the importance of assessing preferences, providing greater choice in the treatment received, and in the location where care is delivered. In order to meet needs and for optimal outcomes, patients must be engaged and have access to affordable and holistic cancer care. The team must be adequately staffed, trained and coordinated, and care must be evidence based (Ferrell et al., 2015; Nekhlyudov, Levit, Hurria, & Ganz, 2014; Spinks et al., 2014). A critical component of this team is Complex Illness Support; providing this service early after diagnosis has been shown to benefit patients and the health care system with improved symptom control, decreased hospitalizations, and increased quality of life (Temel et al., 2010; Ferrell et al., 2015; Ferris et al., 2009;). Providing Complex Illness Support alongside standard oncology care appears to be acceptable, beneficial, and feasible with incurable cancer patients.

**Limitations and suggestions for improvement**

This project represents a limited convenience sample of patients at one site, and the majority of patients were white females. Although the sample was adequate for exploratory purposes related to this project, results cannot be generalized, and statements cannot be made regarding causation. Limitations in methodology are acknowledged, with small sample size and the smaller number of patients appropriate for evaluation of symptom management and satisfaction with the Complex Illness Support team. Selection bias is a concern in recruiting from a single clinic in a single center. Randomized sampling was not possible due to the small focus of this project and limited availability of Complex Illness Support team members. Ethically, this investigator did not feel it was appropriate to randomize due to the strong belief that all patients with life limiting disease have the right to Complex Illness Support, symptom management, advance planning, and participation in setting goals of treatment. Evaluation of symptom severity through patient report and descriptors was subjective. For the two symptom patients evaluated, the provider following the patient was consistent throughout the project. Patients were often referred late after diagnosis, and so Complex Illness Support probably had little effect on chemotherapy decisions. Formal evaluation of additional endpoints and a longer time to follow patients may have provided more information related to benefits of Complex Illness Support.

**Suggestions for Future Clinical Projects**

The degree to which Complex Illness Support intervention could be generalized to other oncology clinicians and patient populations requires further study.

Incorporating multiple sites, additional providers, and differing diagnosis with a more demographically diverse population would provide additional information about Complex Illness Support in general, as well as specific to the oncology population.

Several gaps remain regarding Complex Illness Support. First, this project could not discern the association between palliative care interventions and outcomes. Future research should be focused on identifying the efficacious components of Complex Illness Support. Second, developing a standardized and validated measurement tool to assess patient-reported outcomes appropriate for this population (Kavalieratos et al., 2016) would be incredibly beneficial. Third, future studies comparing patient outcomes with standard oncology care with and without Complex Illness Support would provide prospective data between the populations; this would be possible if those who either refused consultation or were not referred to this service were used as a control group. Fourth, further research is needed to investigate the cost/benefit analysis and feasibility of outpatient Complex Illness Support services. Finally, it will be important to establish research models of care looking at Complex Illness Support delivery that help caregivers in additions to patients.

### **Conclusion**

Information obtained from this project adds to the growing body of evidence supporting the utilization of Complex Illness Support in the outpatient setting for patients with incurable cancer. This model of care offers an approach to improve patient care and outcomes, but also to enhance standard oncology practice in aligning with national standards to provide the highest quality cancer care. Incurable cancer patients

have substantial need for supportive care, and this evidence-based project highlights the contributions that outpatient Complex Illness Support can make. By integrating this service alongside standard oncology care early in disease trajectory, the patient may be better equipped to manage symptoms, discuss goals of care, and participate in advance planning. Despite the limitations and small scope of this project, data and information obtained suggests that there may be a beneficial effect of integration of Complex Illness Support in the cancer patients' experience, most effectively located in the cancer center where patients receive most of their care.

It is evident from this project that oncology patients can be co-managed between Complex Illness Support and oncology, with referral to other specialists as needed. Complex Illness Support adds the patient experience and dimension to deciding cancer treatment. Without patient input and values, information to make treatment decisions is based on lab tests, numbers, scans, and physician opinion. Patients want to have open and honest communication, to be empowered in making decisions based on their goals. Complex Illness Support early after diagnosis of incurable cancer allows relationship building and early discussions, rather than consultation at times of difficult discussions at a time of crisis.

Complex Illness Support must be offered where the patient receives care in order to be successful. There must be close communication between providers to have seamless care of seriously ill patients. Continuity of care is best provided with holistic and complete care of patients within one health system. This project has demonstrated

that Complex Illness Support is accepted and supported by patients and providers, making this a feasible outpatient service.

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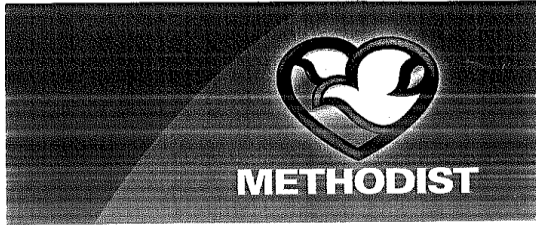
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Appendix A: Complex Illness Support Patient Brochure



**Complex Illness Support Team**

*Being diagnosed with a complex illness, like cancer, can be overwhelming and impact many facets of your life. The Complex Illness Support Team is here to ensure your needs are recognized and met.*

We will spend any amount of time needed to help you and your family fully understand your condition, care options and other needs.

Both cancer and cancer treatment(s) may cause uncomfortable symptoms and create feelings that can be hard to manage. Our doctors and nurse practitioners provide expert treatment to help you achieve maximum possible relief from symptoms such as:

- Pain
- Anxiety
- Breathlessness
- Fatigue
- Nausea
- Depression
- Constipation
- Sleeplessness

*see other side*



(402) 354-5858

As part of your integrated cancer care team, we collaborate actively with your other physicians and health professionals to provide:

- Ideas to help you feel better and healthier
- Medications to reduce symptoms
- Techniques that may not require medications to control or cope with symptoms
- Time to discuss your healthcare goals and changing needs throughout the course of your illness
- Help navigating the healthcare system and community resources
- A sounding board to help you talk through difficult or complex treatment choices
- Assistance coordinating emotional and spiritual support for you and your family
- Planning for unexpected events so you and your family always feel prepared

Your oncologist may refer you to our team, or you may schedule appointments as needed. Services of our physicians and nurse practitioners are covered by most insurance providers. To talk with a member of the Complex Illness Support Team, or learn more about how we can help you manage your cancer and accompanying symptoms, call (402) 354-5858.

Appendix B: Clinical Site Approval Letter



8303 Dodge Street  
Omaha, NE 68114  
(402) 354-5890 phone  
(402) 354-8533 fax

[www.bestcare.org](http://www.bestcare.org)

Daniel D. Lydiatt, MD  
Medical Director

Josie Abboud  
Vice President

Patty Bauer  
Service Executive

September 7, 2016

To Whom It May Concern:

I am writing this letter in support of Kim Bland, Oncology Nurse Practitioner at Methodist Hospital. Kim is enrolled in the Doctor of Nursing Practice program at Nebraska Methodist College. She has my approval to use the Methodist Estabrook Cancer Center Lung/Thoracic Oncology Clinic and patients for her capstone project involving the integration of Palliative Care.

Sincerely,

A solid black rectangular box used to redact the signature of the sender.

Patty Bauer, MSHA, RN, RRT  
Service Executive  
Oncology Services  
Methodist Hospital

Appendix C: Patient Satisfaction Survey Tool

**Complex Illness Support**

Please take a moment to complete this survey. Your answers will help us to improve our program.

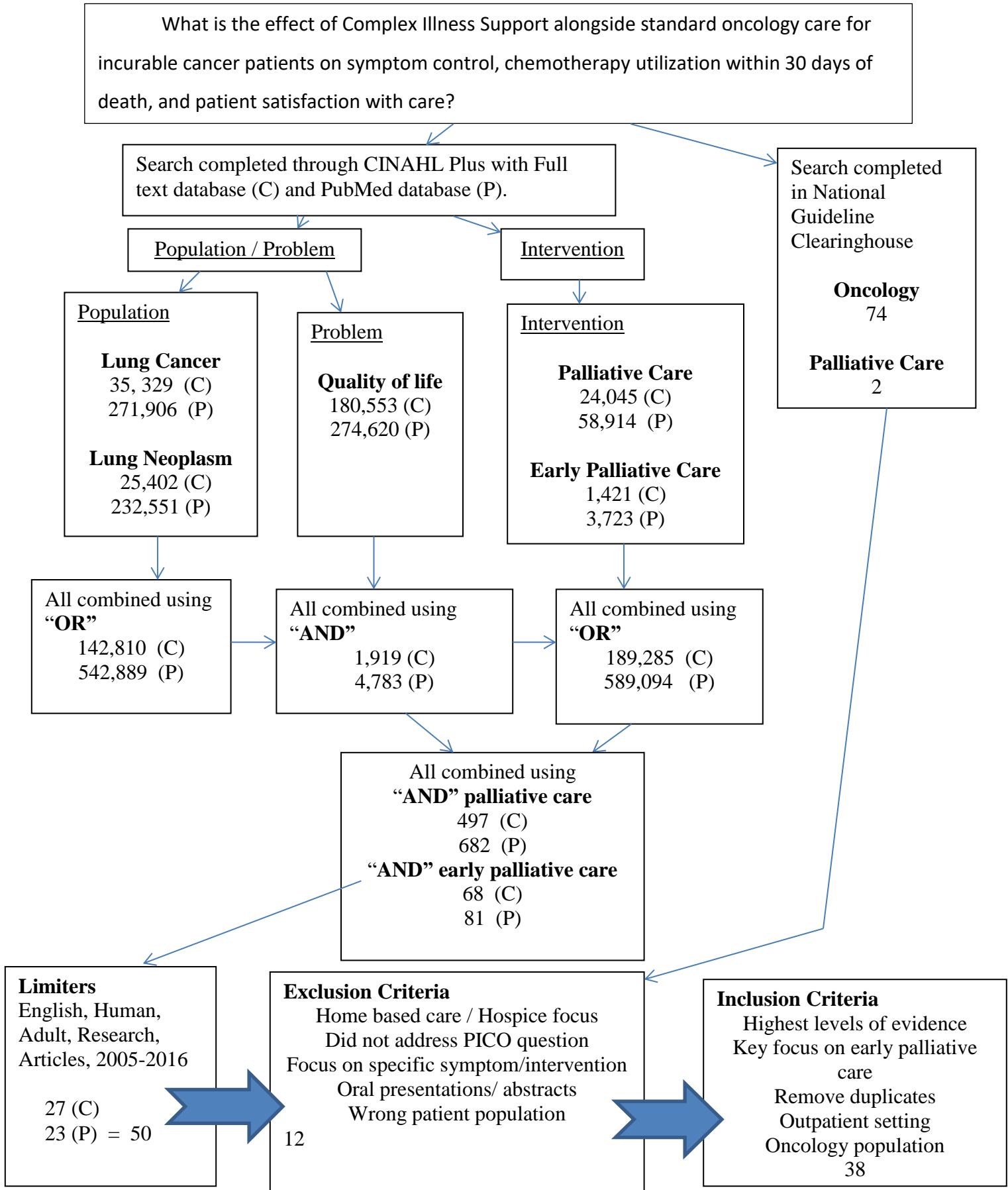
**Please rate your level of agreement with each statement by placing an X in your selected box.**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Somewhat Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
<b>1. The Complex Illness Support team was respectful and professional.</b>					
<b>2. I was able to talk about my goals and preferences for future care.</b>					
<b>3. The team helped me to feel more comfortable (relief from physical and emotional symptoms).</b>					
<b>4. The Complex Illness Support team helped to coordinate my care.</b>					
<b>5. I am satisfied with the Complex Illness Support team.</b>					

Thank you for your time in completing this survey.



Appendix D: Literature Search Flow Diagram



## Appendix E: Approval to use Conceptual Model

**Approval to use Conceptual Model**

**From:** Hui, David [mailto:DHui@mdanderson.org]  
**Sent:** Tuesday, September 20, 2016 9:29 AM  
**To:** Bland, Kim  
**Subject:** RE: Conceptual model for integration of palliative care into oncology

Yes, you have our permission to use this diagram. The original article for this figure is: Integrating Supportive and Palliative Care in the Trajectory of Cancer: Establishing Goals and Models of Care. J Clin Oncol September 1, 2010 vol. 28 no. 25 4013-4017.

Thanks!

Cheers

*David Hui, MD, MSc*

FCT5.6046

Unit 1414 – MD Anderson Cancer Center

1515 Holcombe

Houston, TX, 77030

E-mail: [dhui@mdanderson.org](mailto:dhui@mdanderson.org)

745, 794, 792, 2-6258

**Administrative Assistant: Ms. Sarai Portal**

Phone: 713-794-1803

Fax: 713-792-6092

E-mail: [SNPortal@mdanderson.org](mailto:SNPortal@mdanderson.org)

**From:** Bland, Kim [mailto:Kim.Bland@nmhs.org]  
**Sent:** Tuesday, September 20, 2016 6:40 AM  
**To:** Hui, David <DHui@mdanderson.org>  
**Subject:** RE: Conceptual model for integration of palliative care into oncology

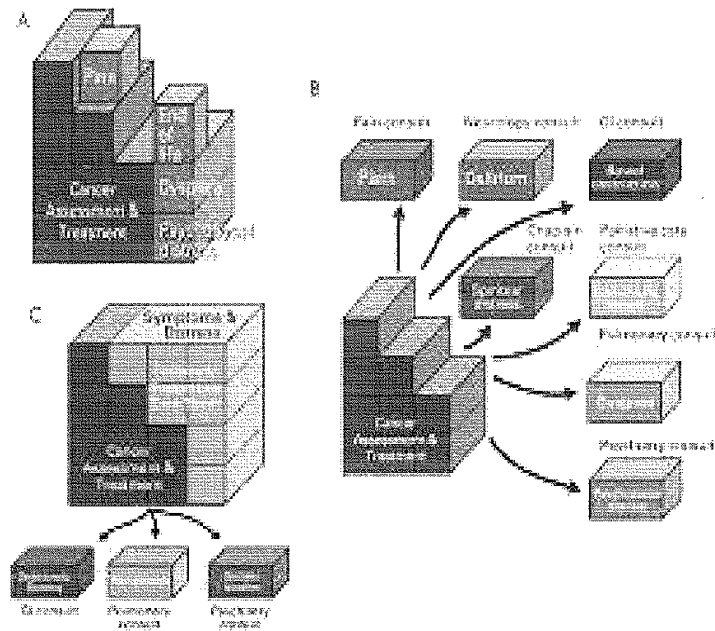
Good afternoon,

I am currently an Oncology / Palliative care Nurse practitioner, and in the final year of my Doctorate of Nursing Program at Nebraska Methodist College. Our institution has a very active inpatient palliative care program, but does not offer this support in the cancer center. My Capstone project is integrating palliative care into the lung cancer clinic with incurable patients. I would like to use the Conceptual model for integration of palliative care and supportive care into oncology developed at MD Anderson.

Thank you for considering this request.

Models of integration of oncology and palliative care - Hui ...

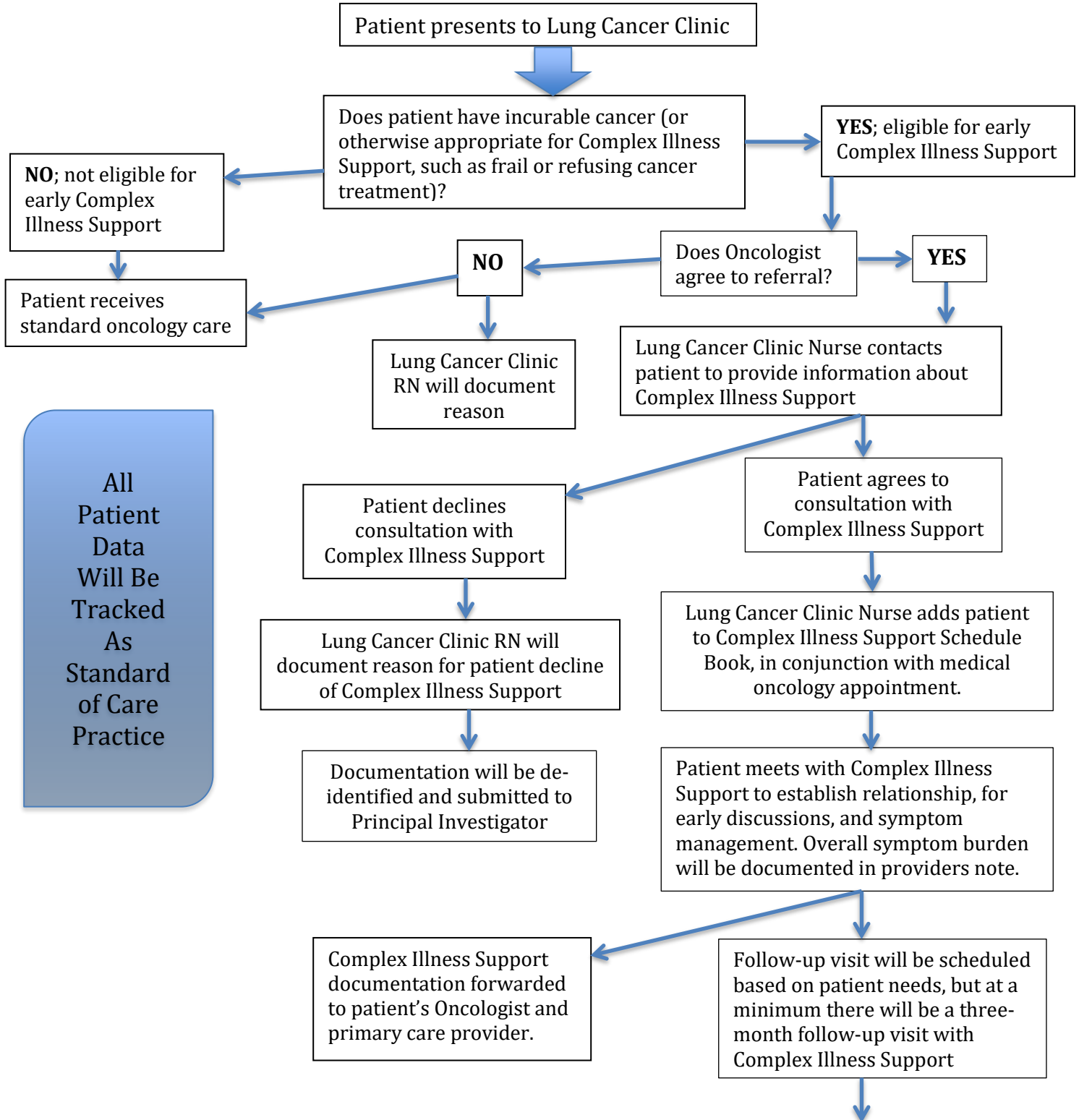
(A) Solo practice; (B) congress approach; (C) integrated care approaches.  
 Reprinted with permission from The University of Texas MD Anderson Cancer Center ...



Sincerely,

Kim Bland, MS, APRN, AOCN  
 Nurse Practitioner  
 Nebraska Methodist Hospital  
 8303 Dodge Street  
 Omaha, NE 68114  
 ph: 402-354-5144  
 fax: 402-354-7885

Appendix F: Patient Flow Algorithm



All Patient Data Will Be Tracked As Standard of Care Practice

- At three-month visit:
- There will be an assessment of overall symptom burden, which will be documented in providers note.
  - The patient will complete a satisfaction survey tool, which will be returned to lung cancer clinic staff, de-identified, and returned to the Principal Investigator.

Appendix G: Principal Investigator CITI Training

**COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)  
COURSEWORK REQUIREMENTS REPORT\***

\* NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for det: See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.

- Name: Kim Bland (ID: 1440236)
- Email: kim.bland@nmhs.org
- Institution Affiliation: Nebraska Methodist Hospital (ID: 361)
- Institution Unit: oncology research
- Phone: 402-354-5144
  
- Curriculum Group: Human Research
- Course Learner Group: Biomedical Research Investigators and Key Personnel
- Stage: Stage 1 - Basic Course
  
- Report ID: 14981888
- Completion Date: 01/19/2015
- Expiration Date: 01/18/2017
- Minimum Passing: 80
- Reported Score\*: 89

**REQUIRED AND ELECTIVE MODULES ONLY**

	<b>DATE COMPLETED</b>
Nebraska Methodist Hospital	01/17/15
Belmont Report and CITI Course Introduction	01/17/15
History and Ethics of Human Subjects Research	01/17/15
Basic Institutional Review Board (IRB) Regulations and Review Process	01/17/15
Informed Consent	01/17/15
Social and Behavioral Research (SBR) for Biomedical Researchers	01/17/15
Records-Based Research	01/17/15
Genetic Research in Human Populations	01/17/15
Populations in Research Requiring Additional Considerations and/or Protections	01/17/15
Vulnerable Subjects - Research Involving Prisoners	01/17/15
Vulnerable Subjects - Research Involving Children	01/17/15
Vulnerable Subjects - Research Involving Pregnant Women, Human Fetuses, and Neonates	01/17/15
Avoiding Group Harms - U.S. Research Perspectives	01/17/15
FDA-Regulated Research	01/17/15
Research and HIPAA Privacy Protections	01/17/15
Conflicts of Interest in Research Involving Human Subjects	01/19/15

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

**CITI Program**  
 Email: [citisupport@miami.edu](mailto:citisupport@miami.edu)  
 Phone: 305-243-7970  
 Web: <https://www.citi-program.org>

**COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)  
COMPLETION REPORT - PART 1 OF 2  
COURSEWORK REQUIREMENTS\***

\* NOTE: Scores on this **Requirements Report** reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.

- Name: Alice Kindschuh (ID: 1930961)
- Email: [alice.kindschuh@methodistcollege.edu](mailto:alice.kindschuh@methodistcollege.edu)
- Institution Affiliation: Nebraska Methodist Hospital (ID: 361)
- Institution Unit: College of Nursing
- Phone: 402-354-7845
  
- Curriculum Group: Human Research
- Course Learner Group: Social Behavioral Research Investigators and Key Personnel
- Stage: Stage 2 - Refresher Course
  
- Report ID: 21091568
- Completion Date: 06-Oct-2016
- Expiration Date: 06-Oct-2018
- Minimum Passing: 80
- Reported Score\*: 100

**REQUIRED AND ELECTIVE MODULES ONLY**

	DATE COMPLETED	SCORE
SBE Refresher 1 – Defining Research with Human Subjects (ID: 15029)	06-Oct-2016	2/2 (100%)
SBE Refresher 1 – Privacy and Confidentiality (ID: 15035)	06-Oct-2016	2/2 (100%)
SBE Refresher 1 – Assessing Risk (ID: 15034)	06-Oct-2016	2/2 (100%)
SBE Refresher 1 – Research with Children (ID: 15036)	06-Oct-2016	2/2 (100%)
SBE Refresher 1 – International Research (ID: 15028)	06-Oct-2016	2/2 (100%)
Biomed Refresher 1 - Instructions (ID: 960)	06-Oct-2016	No Quiz
SBE Refresher 1 – History and Ethical Principles (ID: 936)	06-Oct-2016	2/2 (100%)
SBE Refresher 1 – Federal Regulations for Protecting Research Subjects (ID: 937)	06-Oct-2016	2/2 (100%)
SBE Refresher 1 – Informed Consent (ID: 938)	06-Oct-2016	2/2 (100%)
SBE Refresher 1 – Research with Prisoners (ID: 939)	06-Oct-2016	2/2 (100%)
SBE Refresher 1 – Research in Educational Settings (ID: 940)	06-Oct-2016	2/2 (100%)
SBE Refresher 1 – Instructions (ID: 943)	06-Oct-2016	No Quiz

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Verify at: <https://www.citiprogram.org/verify/76d2667bb-d6df-4f0b-8c2f-43bbde5fa53b>

**CITI Program**  
 Email: [support@citiprogram.org](mailto:support@citiprogram.org)  
 Phone: 888-528-5929  
 Web: <https://www.citiprogram.org>

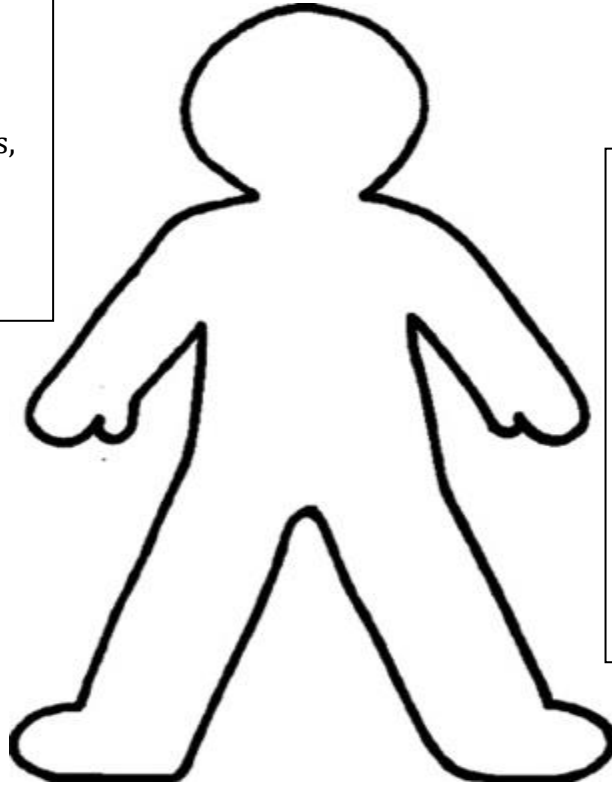
Appendix H: Participant Symptoms

**Head:**

Confusion, Anxiety,  
Depression, Mental  
Decline and Distress,  
Insomnia, Vertigo,  
Bleeding Gums,  
Odynophagia,  
Non-Compliance

**Pain:**

Bone  
Brain  
Leg  
Back  
Neck  
Headache  
Hip  
Abdominal  
Generalized  
Emotional



**Chest:**

Dyspnea, Cough

**Abdomen/GI:**

Nausea, Constipation,  
Weight Loss, Poor  
Appetite

**General:**

Edema, Neuropathy,  
Weakness, Fatigue,  
Debility, Frail

Appendix H: Interventions provided by Complex Illness Support

