2016

Piloting an Intervention to Improve Continuity in Lung Cancer Patients

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Recommended Citation
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Summer 2016

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Acknowledgements

I must acknowledge the following very special individuals for their help throughout my DNP journey. I want to thank my mother, Venice Branham, my first and most shining example of how nurses can make a positive difference in the world. Thank you to my advisors, Dr. Peggy Hickman and Dr. Debra Anderson. Dr. Hickman provided expert guidance during the first half of the journey and Dr. Anderson led me across the finish line. Without Dr. Anderson’s warm encouragement and unwavering support, I might have never made it through this program. I want to thank Dr. Audrey Darville, clinical mentor extraordinaire. Dr. Darville believed in my project, gave me the confidence to see it through and, by her fine example, challenged me to express my ideas more clearly and succinctly. I want to thank Dr. Debbie Hampton who expertly critiques manuscripts faster than anyone I know and was tremendously helpful in this capacity. Thanks to Kathy Collins for shepherding all the DNP students, and especially me, through this program with such grace and kindness. Many thanks to my children, Adam and Rachel, for their patience and support. I would like to thank Brian for his love and support and our dog, Martini, who showed his staunch support by remaining curled up at my feet as I typed this manuscript. Finally, I would like to thank my patients for allowing me to accompany them on their journeys that are sometimes very sad but along the way there is hope, humor and healing even when there is no cure. As a nurse, I have always tried to be there for my patients but they have also been there for me. I am profoundly grateful to the patients who participated in this study and voiced their belief that continuity is important from the very beginning of the cancer trajectory. Life is the ultimate journey and “we are all just walking each other home” – Ram Dass
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In 2015, almost 27% of all cancer deaths were attributable to lung cancer, making lung cancer the leading cause of cancer deaths in the United States. Kentuckians have the highest incidence and mortality rates for lung cancer in the nation with people living in the resource challenged eastern region of the state most severely affected. Kentuckians facing a lung cancer diagnosis are at great risk for care fragmentation due to the complexities associated with the diagnosis, staging and treatment of the disease and transitioning from primary to specialty care. A lung cancer diagnosis often requires that patients leave their communities and trusted primary care providers to seek care from cancer specialists. When communication between primary and specialists is poor, relationships between patients and their primary care providers can suffer. This may lead to inadequate management of comorbid conditions including anxiety, depression and psychosocial distress. This is problematic because patients who are facing a diagnosis of lung cancer are more likely to have anxiety, depression or psychosocial distress than patients with any other type of cancer. In the absence of effective information exchange, relationships between primary care providers and their patients can be interrupted for many months as patients undergo diagnosis, staging and treatment. Such gaps can make resuming care difficult for primary care providers if they have not been adequately informed of their patient’s progress throughout the cancer trajectory. This situation may result in patients lacking an important source of care and support during the diagnostic and treatment phases as well as at the end of life if cancer proves to be incurable.

This practice inquiry project (PIP) is focused on examining the relevant issues facing Kentuckians with a potential diagnosis of lung cancer as they transition between
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primary care and specialist care during the diagnostic, staging and surgical treatment phases of the disease. The first manuscript is a literature review conducted to examine the existing literature to determine whether there are interventions or care models which have been shown to improve continuity of care and patient outcomes in lung cancer patients during the diagnostic, staging, and treatment phases as patients transition between primary and specialty care. The literature was also examined for valid and reliable instruments to measure perceived continuity of care across the primary to specialty care interface.

The second manuscript describes the development of an intervention to improve three types of continuity, relational continuity (RC), information continuity (IC) and management continuity (MC), for patients facing a lung cancer diagnosis as they undergo diagnosis, staging and surgical treatment and transition from primary to specialty care. The characteristics of Kentuckians and the continuity-related characteristics of the health care system that serves them are examined and used to inform the intervention. This manuscript also describes the selection of an instrument to measure perceived continuity in this population. A patient-centered outcome that is meaningful to this population and is likely to change due to the intervention is also selected.

The final manuscript describes a pilot intervention in forty patients at an NCI-designated cancer center serving Kentuckians. The purpose of the pilot was to determine feasibility and effect of a nurse-led intervention to improve all three types of continuity for patients who are transitioning between primary and specialty care as well as to assess the effect of perceived continuity of care on patient distress levels.
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This practice inquiry project led me to identify a problem from clinical practice, examine the existing literature for relevant issues, assess the population and system for contributing factors, develop and pilot an intervention and evaluate the outcomes.
Literature Review: Continuity of Care in Early Stage Lung Cancer

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Abstract

Purpose: Patients facing a lung cancer diagnosis are at high risk for care fragmentation due to the complexities associated with the diagnosis, staging and treatment of the disease, and transitioning from primary to specialty care. The purpose of this literature review is to identify relevant issues, terminology, care models, and interventions used to improve continuity in lung cancer patients during the diagnostic, staging, and treatment phases as patients transition between primary and specialty care.

Methods: A literature search was performed using Google Scholar, PubMed, CINAHL, and the Cochrane Database of Systematic Reviews from January 1998 to January 2015. A separate but related search was performed to identify scales to measure continuity of care from the patient’s perspective using the previously mentioned databases. Key words include: continuity in lung cancer care, continuity metrics, interventions to improve continuity in cancer care, qualitative research, and continuity of cancer improving continuity of care across the primary to specialty care interface. Preference was given to meta-analyses, systematic reviews, and randomized controlled trials.

Results: Of the 2643 studies located, 17 articles met the predefined criteria and were reviewed. Studies included two meta-analyses, two systematic analyses, and one meta-summary. Research shows there is a paucity of high-quality evidence supporting specific interventions to improve continuity of care in cancer patients.

Conclusions: The existing body of research included several successful nurse-led interventions that improved physical and/or psychosocial outcomes, but the current body of research does not allow for firm conclusions to be drawn about which interventions or care models are most likely to improve continuity-related outcomes. There may be some weak evidence that interventions to improve continuity of care may result in decreased
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social needs, improved satisfaction, and improved quality of life. As an aggregate, the studies did not generally support improvements in physical or functional status. Psychological status was found to be poorer in some receiving interventions aimed at improving continuity. Evidence regarding continuity of care in early-stage lung cancer is also limited. Patients’ perceptions of continuity of care across the primary to specialty care interface can be reliably measured using a validated instrument such as the Nijmegen Continuity Questionnaire (NCQ) (Uijen et al., 2011).

Future Implications: Additional exploration of effective interventions to improve continuity of care for lung cancer patients at the primary to specialty care interface is clearly needed. Researchers have suggested that any effective interventions will need to be multifaceted, target all three types of continuity (Relational Continuity, Information Continuity and Management Continuity), and include measured improvement of continuity of care, as well as at least one outcome that is meaningful to the population and sensitive to change as a result of a continuity intervention (Aubin et al., 2012).
Continuity of Care and Distress in Early Stage Lung Cancer

The diagnosis of lung cancer is a catastrophic health event. According to the SEER (2015) database, an estimated 221,200 new cases of lung cancer were diagnosed in the United States, accounting for 13.3% of cases in 2015. In the same year, the database estimated the number of lung cancer deaths at 158,040, representing 26.8% of all cancer deaths and making lung cancer the leading cause of cancer deaths in the United States. At this time, only 17.4% of all patients diagnosed with lung cancer will survive five years (SEER, 2015). Early detection is critical for improving five-year survival rates. Data from 2010 to 2012 demonstrate that 6.6% of men and women will receive a diagnosis of lung cancer in their lifetime. Understandably, patients can experience high levels of emotional distress when facing a lung cancer diagnosis.

The accurate diagnostic and staging process for lung cancer is complex, often taking several weeks to complete. This process is vital to selecting the most effective treatment plan to prolong survival. According to SEER, only 15.6% of patients are diagnosed with localized disease that may be curable by surgical resection; comparatively, the five-year survival for localized cancer of the lung is 54.8%. Specialists that may not be available in a patient’s community are often needed to perform a series of diagnostic procedures and staging procedures. Patients can experience anxiety and distress when leaving their communities and primary care providers (PCPs) for larger medical centers.

Before transitioning to specialist care, most patients have had an ongoing relationship with a PCP who has a thorough knowledge of their medical and social histories (Phillips et al., 2009). Patients view their PCPs as trusted sources of information.
regarding cancer treatments and support (Whelan et al., 2009). PCPs often make the initial discovery of findings that are suspicious for lung cancer and refer their patients to oncology specialists. Gaps in care can occur when PCPs do not receive timely information about their patient’s progress throughout the diagnostic, staging and treatment process. PCPs may also have difficulty with resuming follow-up care when there are gaps in communication between health providers. From the time of diagnosis through treatment, 40% of cancer patients report having unmet needs regarding information about their disease, treatments and psychosocial support (Sussman & Baldwin, 2010). Improved continuity of care between PCPs and specialists could provide a foundation of much needed support for patients facing a lung cancer diagnosis.

In 2013, The Institute of Medicine (IOM) advised that members of cancer care teams should coordinate with each other and with primary and specialty care teams to implement patient care plans and deliver comprehensive, efficient, patient-centered care (IOM, 2013). The IOM made several recommendations regarding PCP involvement which include managing comorbid medical conditions, building relationships with patients and oncology team members to improve continuity, eliciting patient preferences, and clarifying goals of care (National Research Council, 2013). Despite these recommendations, discontinuities across the primary to specialty care interface frequently occur. This can be due to a lack of or delayed communication between primary and specialty care providers (Oeffinger, 2006), a lack of understanding or agreement about which provider will treat comorbid conditions including pain, anxiety and depression, and an overall lack of care coordination (Bickell & Young, 2001; Earle & Neville, 2004; Earle, 2006). While it is clear that improving continuity of care for lung cancer patients
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will require the coordinated efforts of both primary and specialty care providers, it is not clear which specific interventions or care models are most likely to improve the care experience for patients facing a diagnosis of lung cancer.

The main purpose of this review is to examine the existing literature to determine whether there are interventions or care models which have been shown to improve continuity of care and patient outcomes in lung cancer patients during the diagnostic, staging, and treatment phases as patients transition between primary and specialty care. The literature will also be examined for valid and reliable instruments to measure continuity of care across the primary to specialty care interface.

**Continuity of Care and Lung Cancer**

Continuity is defined as “how one patient experiences care over time as being coherent and linked; continuity is the result of good information flow, good interpersonal skills and good coordination” (Reid, Haggerty, & McKendry, 2002). Three aspects of continuity include: Information continuity (IC), which refers to the ability and use of information regarding prior events to make current care relevant and appropriate; relational continuity (RC), which describes the ongoing relationship between a patient and providers; and management continuity (MC), which is the provision of timely and complementary services within a shared management plan (Reid et al., 2002). Due to comorbidities and other conditions, continuity across the primary to specialty care interface is important for patients during the diagnostic, staging and treatment phase of lung cancer.

The incidence of lung cancer is higher in the elderly; the average age at the time of lung cancer diagnosis is 70 years of age and two out of three people diagnosed with
l lung cancer are 65 or older (American Cancer Society, 2015; Yancik & Ries, 2004). Comorbid conditions, more prevalent among the elderly, are associated with worse lung cancer survival (Asmis et al., 2008; Islam, Jiang, Angondowati, Lin, & Ganti, 2015). A majority of patients (73.3%) have comorbid conditions at diagnosis, with the most common being chronic pulmonary disease, diabetes, and congestive heart failure (Islam et al., 2015). Untreated comorbidities may prevent complete diagnostic evaluation and lead to less accurate staging, thereby influencing treatment selection and resulting in patients receiving less aggressive treatment (Iachina, Green, & Jakobsen, 2014; Islam et al., 2015; Tammemagi, Neslund-Dudas, Simoff, & Kale, 2003). Many patients with early-stage, potentially curable cancers are considered ineligible for surgery due to impaired lung function or comorbid disease (Dransfield, Lock, & Garver, 2006). As such, PCPs can optimize health status so more patients will be eligible for surgical resection, which is the treatment of choice for optimizing outcomes in lung cancer.

The prevalence of clinically significant psychosocial distress is very high among patients with newly diagnosed lung cancer (Steinberg et al., 2009). Lung cancer patients have high rates of mixed anxiety and depression; this is associated with poorer treatment outcomes, worse quality of life, decreased treatment adherence, slower recovery, increased risk for suicide, and higher health care costs (Brintzenhofe-Szoc, Li, Kissane, & Zabora, 2009). Primary care providers are generally more familiar with their patients and with the management of these comorbidities, including psychosocial distress, anxiety and depression. The effective management of psychosocial comorbidities during the diagnostic, staging and treatment phases may decrease distress levels and improve adherence to treatment.
METHODS

A literature search to identify relevant issues, terminology, care models and interventions used to improve continuity in lung cancer patients during the diagnostic, staging and treatment phases as patients transition between primary and specialty care was performed using Google Scholar, PubMed, CINAHL and the Cochrane Database of Systematic Reviews. This search did not yield any articles, so a broader search was conducted to include improving continuity and outcomes in cancer patients. A separate but related search was performed to identify scales to measure continuity of care from the patient’s perspective using the previously mentioned databases. The reference lists of included studies and reviews were also scanned for relevant reports and studies on the subject of improving continuity of care for cancer patients, especially during the diagnostic and treatment phases. Search terms included: continuity in lung cancer care, continuity metrics, interventions to improve continuity in cancer care, qualitative research, and continuity of cancer improving continuity of care across the primary to specialty care interface. Two meta-analyses, two systematic analyses and one meta-summary were found and will be discussed in this review.

QUANTITATIVE RESEARCH

Aubin et al. (2012) performed the most comprehensive meta-analysis to date of fifty-one studies of interventions designed to improve continuity of care for cancer patients. Selection criteria included randomized controlled trials, controlled clinical trials, controlled before and after studies and interrupted time series evaluating interventions to improve continuity of care in cancer patients. To be included in the meta-analysis, studies had to involve a majority of adults with cancer or healthcare providers of adults with
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cancer. Primary outcomes considered for inclusion were processes of health care services, objectively measured healthcare professional responses, informal caregiver/patient outcomes, and self-reported measures performed with instruments deemed valid and reliable.

The fifty-one studies included in the meta-analysis included information about three different models: case management, shared care, and interdisciplinary teams. Additional interventions included patient-held records, telephone follow-up, communication, and case discussion between distant health professionals, change in medical record systems, care protocols, directives and guidelines, and coordination of assessments and treatments. After analyzing the studies, Aubin et al. (2012) concluded that based on the median effect size estimates, there were no significant differences between patients assigned to the intervention groups and those assigned to the usual care group. A small number of studies reported improved psychological health, provider satisfaction, or process of care measures (health care utilization, care coordination, accessibility to care, continuity of care as well as availability and transfer of information), but due to the high heterogeneity among studies, they could not be regrouped to calculate median effect size estimates. The authors stated the main limitations of the review were the differences between the studies including designs, phase of care, interventions, numbers and characteristics of participants, measured outcomes, healthcare settings and follow-up intervals.

Aubin et al. (2012) recommended that future continuity research focus on determining which outcomes are most sensitive to change and elicit the most meaningful outcomes related to continuity of care. The development of a standardized instrument to
measure continuity of care in patients with cancer could be helpful in advancing continuity research (Aubin et al., 2012; Reid et al., 2002). Of the 51 studies included in the meta-analysis, King et al. (2009) conducted the only study that specified continuity as an outcome and found that high levels of perceived continuity in cancer patients are associated with reduced needs for future care and improved quality of life and psychosocial outcomes. The biases identified most frequently were inadequate allocation concealment, inadequate management of incomplete data, contamination between experimental groups and lack of blinding in most studies (Aubin et al., 2012).

For purposes of analysis, Aubin et al. (2012) grouped studies according to the type of continuity targeted (RC, IC or MC) or to the type of model of care or interventional strategy. The authors then calculated the effect size of interventions designed to improve physical status, psychological status, social needs, or satisfaction by comparing the difference between the median scores rather than the mean scores between the groups. Aubin et al. (2012) determined that for cancer patients across multiple settings, interventions designed to improve any type of continuity resulted in no effect on functional status or physical status. When comparing patients in the intervention groups versus patients in the control groups, the greatest effect size was found in the satisfaction domain (6.7) followed by global quality of life (2.05). Patients in the intervention groups experienced lower psychological status (0.24) and lower social needs (0.71). This data is based on calculating median effect sizes using 95% confidence intervals. The authors note that the quality of evidence is very low in every category due to the lack of or unclear blinding, heterogeneity of the population, interventions and outcomes, and unclear sequence generation during the process of randomization.
Nurse-Led Interventions to Improve Physical Status

While the complete analysis failed to show an overall effect for continuity interventions, four studies (Jordhoy, Fayers, Loge, Ahlner-Elmqvist, & Kaasa, 2001; McCorkle et al., 2009; Moore et al., 2002; Oleske & Hauck, 1988) among 51 studies included in the meta-analysis (Aubin et al., 2012), found improvements in the physical status of patients who received interventions designed to improve all three types of continuity (RC, MC, IC). Oleske & Hauck (1988), Moore et al. (2002), and McCorkle et al. (2009) all showed improvements in at least one aspect of physical status. Oleske & Hauck (1988) conducted a randomized controlled trial to test the effects of the services of an oncology nurse specialist (ONS) and continuing education as compared to a continuing education program without the services of an ONS on patient outcomes such as utilization and acceptability of home health care services and mortality. They randomized 874 patients with any type of cancer in any phase of care to one of three groups. Two groups received an intervention: Oncology nurse specialist involvement with continuing education on cancer or continuing education on cancer alone. The third group was an observation only group. Pre and post analysis showed the group that received the services of the oncology nurse specialist and continuing education on cancer experienced a significant increase in home health care acceptance and utilization as well as a significant decrease in cancer-related mortality.

Moore et al. (2002) conducted a randomized study that included 203 lung cancer patients who had completed initial therapy and were expected to survive for at least three months; participants were placed in either a conventional medical follow-up or a nurse led follow-up group. Conventional medical care consisted of a post-operative
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appointment and follow-up appointments at two to three month intervals for medical assessment and to monitor disease progression. Patients could also be seen on an as needed basis. Patients in the nurse follow-up group were allocated to a clinical nurse specialist (CNS) in lung cancer and were assessed monthly by protocol over the phone or in a nurse led clinic to identify signs of disease progression, symptoms requiring intervention, or serious complications. Additional contacts were made as needed in the nurse-led clinics or by phone without an appointment. The CNS was responsible for the triage and care of patients in the nurse-led follow-up group and coordinated referrals for patients deemed to require further medical treatment. The CNS focused on providing information, support, and coordinating input from other agencies or services. The primary outcomes were quality of life and patient satisfaction at three months as compared to baseline. The authors found that patients in the intervention group experienced higher satisfaction, better scores for emotional functioning, less severe dyspnea and less peripheral neuropathy. No differences were seen in length of survival or rates of objective progression between the CNS led follow-up or the conventional medical follow-up.

Patients in the CNS-led follow-up group were more likely to die at home and had fewer appointments with doctors and fewer radiographs.

McCorkle et al. (2009) randomized 149 women suspected of having a primary diagnosis of ovarian cancer following abdominal surgery to either a specialized care or control group. Patients in the intervention and control groups received a Symptom Management Toolkit (SMT) (Given, Given, & Espinosa, 2003), a manual written at the 6th-grade level, which provided information on 16 symptoms commonly experienced by patients who have had surgery or chemotherapy. The intervention group received
specialized care by an advanced practice nurse (APN) which included symptom management and monitoring, emotional support, patient education, coordination of resources, referrals, and nursing care. Women exhibiting high levels of distress were evaluated and monitored by a psychiatric consultation liaison nurse (PCLN). The control group participants were assigned a consistent research assistant trained to use the SMT to help with symptom management. Control group patients who had questions outside of the content of the SMT were directed to call their oncologist. The services with the research assistant included one home visit and three weekly phone calls during the first month after hospital discharge and monthly telephone calls for the remaining five months of the intervention, for a total of eight contacts. Services for the intervention group included 18 patient contacts during the first six months following discharge from the hospital. When compared to controls, the group who received the APN plus PCLN intervention was found to have significantly better physical quality of life over time.

Jordhoy et al. (2001) were unable to show any physical improvement between the intervention group and controls in a cluster randomized controlled trial designed to test the effectiveness of comprehensive palliative care on cancer patient’s quality of life. Eligible participants were patients aged eighteen or older with any incurable malignant disease and a survival expectancy of two to nine months. Subjects were randomized to either conventional care or a new Palliative Medicine Unit (PMU). It was hypothesized that the PMU program would have a positive impact on patients’ health-related quality of life (as measured by the EORTC QLQ-C30, the IES, five social support items and three items of general well-being), including improved pain control better physical and emotional functioning and less psychological distress. However, despite adequate sample
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size and good compliance, there were no significant differences between the intervention and control groups on any quality of life scores. The authors reported that their results were consistent with the findings of earlier RCT’s that evaluated the impact of palliative care programs on patients’ quality of life. The authors suggested one plausible reason for the lack of difference between the intervention and control groups was that the control group had access to good palliative care services and the palliative medicine unit was new. Therefore, there may not have been a significant difference in the services received by either group.

Nurse-Led Interventions to Improve Psychosocial Status

McCorkle et al. (2000), Jordhoy et al. (2001), McLachlan et al. (2001), and McCorkle et al. (2009) examined the psychological status of patients assigned to interventions designed to improve all three types of continuity (RC, MC, IC) versus usual care. McCorkle et al. (2009) and McLachlan et al. (2001) demonstrated significant improvements in psychological status when patients in the interventional groups were compared to those receiving usual care, which is inconsistent with the overall effect noted in the meta-analysis by Aubin et al. (2012).

As previously discussed, McCorkle et al. (2009) demonstrated decreased symptom distress and improved quality of life in a study of 149 women suspected of having a primary diagnosis of ovarian cancer following abdominal surgery. The researchers also demonstrated that patients receiving a specialized APN intervention to provide enhanced symptom monitoring and management, emotional support, patient education, coordination of resources, referrals, and nursing care also experienced improved psychosocial status. Patients monitored by an APN reported less uncertainty
while the patients evaluated and monitored by an APN and PCLN experienced less uncertainty and better psychological quality of life over time. The authors found that the effect of the APN plus PCLN intervention was most effective among the more highly distressed patients as measured by the Distress Thermometer.

McLachlan et al. (2001) looked at 450 patients with cancer of any type in any phase of care. The intervention consisted of psychosocial care based on patient self-assessment using a touch screen computer to complete a self-report questionnaire centered on their cancer-related needs, quality of life, and psychosocial information. The results were made immediately available to the doctor and a coordination nurse during the patient’s visit. The coordination nurse used this information to generate management plans using pre-specified psychosocial guidelines formulated by a multidisciplinary group of experts. The coordination nurse was encouraged to apply her clinical expertise in prioritizing and negotiating referrals and was responsible for plan implementation and coordinating other members of the health care team. There were no significant differences found in cancer needs as measured by the Cancer Needs Questionnaire (CNQ) (Cossich, Schofield, & McLachlan, 2004), quality of life, satisfaction with care, or psychosocial function between the baseline and follow-up assessments. However, patients who were moderately or severely depressed at baseline experienced a significant reduction in depression in the intervention group at the 6-month assessment.

McCorkle et al. (2000) compared depressive symptoms, symptom distress and enforced social dependency between an intervention and control group at baseline and at three and six months post-hospitalization. The researchers conducted a randomized controlled study of 375 patients aged 60 to 92 with newly diagnosed solid cancers that
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were treated surgically. Researchers randomized 199 subjects to an intervention group and 185 subjects to the control group. The intervention was a protocol consisting of standard assessment and management post-surgical guidelines, doses of instructional content, and schedules of contacts. The intervention lasted four weeks and was comprised of three home visits and five telephone contacts provided by APNs. Patients and their family caregivers received comprehensive clinical assessments, monitoring, teaching, and skills training. They found, for the intervention group and controls, all three psychosocial variables were improved at three months and stable at six months. While there were no significant statistical differences between the groups, the authors noted that the intervention group consisted of patients with more late stage cancers.

Jordhoy et al. (2001) found no significant differences in quality of life scores including emotional or psychological distress in their randomized controlled trial designed to test the impact of a comprehensive palliative care intervention in patients with incurable malignant disease with a life expectancy of two to nine months.

Qualitative Studies

Haggerty, Roberge, Freeman and Beaulieu (2013) conducted a meta-summary of qualitative studies regarding the patient’s experience of continuity of care. The purpose of the analysis was to identify measurable, recurring elements that emerge when patients with multiple health conditions see multiple clinicians as the basis for developing a reliable measurement of continuity of care. From an initial list of 514 studies from 1997 to 2007, thirty-three studies met criteria and were reviewed. Several overarching themes were identified.
Continuity Experienced as Security and Confidence

Patients experience continuity of care as a feeling of security (Hildingsson & Thomas, 2007; Radwin, 2000; Bakker, Des Rochers, McChesney, Fitch, & Bennett, 2001) and confidence (McCourt & Pearce, 2000; Harrison & Verhoef, 2002; Tarrant, Windridge, Bouton, Baker & Freeman, 2003; Naithani, Gulliford & Morgan, 2006) rather than seamlessness. Trust is often tied to care coordination with patients feeling more secure when they are connected to a clinician who will assume responsibility for effective care coordination (Radwin, 2000).

Coordination and Information Transfer are Assumed

Coordination and information transfer are assumed until proven otherwise. Studies often specify that coordination is vital to care being connected and coherent, but coordination requires collaboration among clinicians (Haggerty, Roberge, Freeman, & Beaulieu, 2013). There has been little evidence that patients are aware of these actions (Naithani et al., 2006). When care is coordinated, patients feel that clinicians are communicating with one another (Radwin, 2000). Patients are likely to focus on care management only if they experience problems that result in discontinuity (Woodward, Abelson, Tedford, & Hutchison, 2004).

Care Plans are Useful for Clinicians Only

Care plans are helpful for clinician coordination but are not perceived as such by patients. Patients assume that the clinicians involved in their care are working from a shared clinical pathway or plan (Alazri, Neal, Heywood, & Leese, 2006; Ware, Dickey, Tugenberg, & McHorney, 2003; Naithani et al., 2006). Patients do not perceive that simply receiving a copy of the management plan used by clinicians is helpful especially if
the plan does not account for comorbidities (Williams, 2004) or is viewed as unrealistic because it is dependent upon resources or capacity the patient does not possess (Osse et al., 2002; Fraenkel, McGraw, Wongcharatrawee, & Garcia-Tsao, 2006).

**Knowing What to Expect and Having a Contingency Plan is Vital**

Knowing what to expect and having a contingency plan fosters security. Patients often experience discontinuity of care when they transition from inpatient to outpatient and home care settings. They often do not understand institutional and functional boundaries and have difficulty navigating complex health care systems (Haggerty et al., 2013). With every transition, patients should be told what to expect, where to get help and given a contingency plan to return to a safe care environment in case they experience unmanageable distress (Miles, Edwards, & Clapson, 2004; Harrison & Verhoef, 2002; McKinney & Deeny, 2002).

**Information Among Clinicians Experienced Through Gaps**

Patients assume that clinicians are communicating until they experience a gap in continuity that suggests otherwise. Haggerty et al. (2013) found that communication failures were responsible for patients’ experiences of discontinuity in nearly two-thirds of the 33 studies they reviewed. Failure to transfer or use appropriate information becomes evident when important patient comorbidities or life circumstances are ignored (Woodward, Abelson, Tedford, & Hutchison, 2004; Williams, 2004), when clinicians are unaware of other professionals’ treatment decisions (Alazri, Neal, Heywood, & Leese, 2006) or when patients get conflicting messages from their clinicians (Kai & Crosland, 2001).
One Most Trusted Clinician Among Many is Key

Haggerty et al. (2013) found that two-thirds of the studies they reviewed referred to the importance patients placed on having a therapeutic with an individual clinician who had a comprehensive knowledge of the patient as a whole person and used that knowledge when managing health issues (Tarrant, Windridge, Bouton, Baker, & Freeman, 2003; Infante et al., 2004; von Bultzingslowen, Eliasson, Savimaki, & Mattson Hjortdahl, 2006). Having a single, trusted clinician who will treat the patient as a partner and help patients navigate the system reinforces the experience of continuity in the view of the patient (Kai & Crosland, 2001; Williams, 2004; Alazri et al., 2006).

Patients experience continuity as security and confidence rather than seamlessness. Patients take for granted that information continuity and management continuity exist until a disruption occurs, bringing the lack of one or both types of continuity to light. Care plans are viewed by patients as useful for clinicians but not for patients who prefer information that is tailored to their particular set of circumstances. It is relational continuity in the form a single clinician who will keep them informed, partner with them in their care, help navigate the system, serve as a conduit between all their providers, and make contingency plans, if needed, that provides patients with a sense of continuity and security.

The Shared Care Model

Aubin et al. (2012) found that some formal programs, care delivery approaches, roles and interventional strategies used to improve continuity of care are prominent in the literature. Continuity of care interventions are typically multifaceted, combining various components and interdisciplinary approaches such as case conferences, shared written
documentation tools, care guidelines, assessments of patient and family needs and strengths, patient and family education and input in decision-making, care plan implementation, identification of supplemental resources, and integration of care through transitions and evaluation. These components are often encompassed within care delivery models.

Shared care, conceptualized by Hickman, Drummond and Grimshar (1994), is a well-known model that can be used to improve the continuity of care of patients with chronic conditions, such as cancer, across the primary to specialty care interface during any phase of care. The American Society of Oncology (ASCO) endorses a shared care model to take advantage of the expertise of cancer specialists and the PCP in coordinating cancer care and survivor follow-up (McCabe et al., 2013). Shared care refers to the participation of PCPs and specialists in the planned delivery of care for patients with a chronic condition such as cancer. The model involves enhanced information exchange over and above routine discharge summaries and referrals (Hickman et al., 1994; Oeffinger et al., 2006; Smith et al., 2009). Shared cancer care is a variation of shared care in which clinicians from different specialties co-manage patients throughout the cancer continuum from diagnosis to post-treatment surveillance (Oeffinger et al., 2006). Norman, Sisler, Hack, and Harlos (2001) conceptualized a shared cancer care model that includes involvement of both PCPs and the oncology team throughout the trajectory of cancer care.

Successful continuity is highly dependent on the quality of information between clinicians (Aubin et al., 2010; Sada, Street, Singh, & Naik, 2011). In an effort to improve communication across the primary to specialty care interface, Jefford et al. (2008)
conducted a randomized controlled trial in which they assessed the impact of faxing information tailored to a particular patient’s chemotherapy regimen to the patient’s PCP in addition to the usual information provided versus the usual information alone. The information packet focused on possible adverse effects of chemotherapies and recommended management strategies. Primary endpoints were: Confidence treating patients receiving chemotherapy (confidence), knowledge of adverse effects and reasons to refer patient back to the oncology center (knowledge), and satisfaction with information and shared care of patients (satisfaction). The authors found PCPs in the intervention group demonstrated a significantly greater increase in levels of confidence and satisfaction when compared with PCPs who received the usual correspondence. However, no differences were detected for knowledge of adverse effects. The authors concluded that information faxed to PCPs is a simple, inexpensive intervention that increases confidence in managing adverse effects and increases satisfaction with shared care.

Using a shared cancer care model, Sada et al. (2011) undertook a qualitative study to explore PCPs and oncologists perception of roles, responsibilities, and communication patterns in three integrated health systems using electronic health records (EHRs). The authors found that physicians reported EHRs improved communication within the integrated systems, but communication with providers outside the integrated systems was problematic. PCPs reported uncertainties regarding their role in cancer care although oncologists emphasized the importance of PCPs managing co-morbid conditions during all phases of care. Patients and specialists alike felt PCPs were better equipped to manage psychological distress and behavior modification. Sada et al. (2011) concluded that in
integrated health systems, EHRs facilitated shared cancer care through improved
communication. However, strategies to improve communication between providers
outside the integrated systems are needed to improve shared cancer care. Strategies to
facilitate a more active role for PCPs in managing comorbidities, psychological distress
and behavior modification are also needed.

Aubin et al. (2010) performed a prospective longitudinal study of patients with
lung cancer to assess PCP involvement in cancer follow-up during different phases of
care. They found that PCP participation in cancer care was modest, with most patients
reporting they were generally satisfied with their PCPs involvement. However, when
questioned about specific aspects of cancer care, discrepancies emerged between
patients’ perceptions and expectations regarding PCP involvement in coordination of
care, emotional support, information transfer and symptom relief. They found that
patients would have liked their PCP to be more involved in these aspects of care during
all phases of care. Less than 50% of patients reported a high degree of involvement from
their PCPs in most aspects of care, regardless of the phase. Patients reported the least
involvement from their PCPs during the primary treatment phase of cancer, which seems
to confirm that PCPs are often cut off from cancer care at the onset (Aubin et al., 2010).

Smith et al. (2007) explored the effectiveness of shared care health service
interventions designed to improve the management of chronic disease across the primary
to specialty care interface by performing a meta-analysis of the current literature. Twenty
studies were identified and nineteen of these were randomized controlled trials. Most of
the studies involved complex, multifaceted interventions of short duration. The authors
found mixed results but no consistent improvements in physical, mental health,
psychological, or psychosocial measures including measures of disability and function, hospital admissions, default or participation rates, risk factor modification, or patient satisfaction. The only clear improvements in care were associated with prescribing practices in studies that measure this outcome. The authors noted that the methodological quality of studies varied considerably with only a few studies of high-quality design. They concluded that currently, there is not sufficient evidence to support the widespread introduction of shared care services. They recommended more high-quality research prior to the implementation of shared care into standard care practice. The complexity of the interventions may also warrant studies of longer duration to determine the effectiveness and sustainability of shared care over time.

**Measuring Continuity**

Continuity of care is widely recognized as a core value in primary care (Stange & Ferrer, 2009) and is becoming increasingly important to specialists and patients. Aubin et al. (2012) proposed that future research should include continuity of care as an outcome measure. Until recently there has been a dearth of validated instruments designed to measure all three dimensions of continuity of care across the primary to specialty care interface. Uijen et al. (2012) performed a systematic review of instruments designed to measure continuity. Search terms included continuity of care, coordination of care, integration of care, patient-centered care, and case management. The authors searched for articles published between 1995 and October 2011 including articles describing the development and/or evaluation of the measurement properties of those instruments measuring one or more dimensions of continuity, including personal continuity, team continuity and/or cross-boundary continuity.
The types of continuity to which Uijen et al. (2012) refer (personal continuity, team continuity, and cross-boundary continuity) are slightly different than those (relational continuity, information continuity, and management continuity) described by Reid et al. (2002). Personal and relational continuity are similar as they both describe the type of continuity that comes from seeing the same providers over time. Information and management types of continuity are inherent in the provision of both team and cross-boundary continuity. Team continuity refers to communication or information sharing and cooperation to improve management continuity in one setting. Cross-boundary continuity refers to communication or the sharing of information and cooperation in the management of patients between providers in different care settings.

Uijen et al. (2012) performed a systematic review of instruments used to measure continuity that included twenty-four articles describing the development and/or evaluation of instruments. Ten instruments measured all the dimensions of continuity of care. Instruments have been developed for either a particular type of patient or provider. Concerns with the number or quality of assessed measurement properties or the ability to measure all three types of continuity of care were identified. All the instruments designed specifically to measure continuity of care in patients with cancer had problems regarding the limited types of continuity measured, the quality of the measurement properties or the low interpretability of the instruments. For patients with a chronic illness, such as cancer, Uijen et al. (2012) concluded that the Nijmegen Continuity of Care instrument allows for the most comprehensive measurement of continuity of care as it is the only questionnaire that has been validated in primary and secondary care and shows the highest quality of measurement properties and interpretability.
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**Discussion**

There are many challenges to implementing an evidence-based approach to improve continuity from the diagnostic through treatment phase of lung cancer. Importantly, there is a paucity of high-quality evidence supporting specific interventions to improve continuity of care in cancer patients. The existing body of research does not allow one to draw firm conclusions about which interventions or care models are most likely to improve continuity-related outcomes. Aubin et al. (2012) determined that when considering the entire body of continuity research in their meta-analysis, there may be some weak evidence that interventions to improve continuity of care may result in decreased social needs, improved satisfaction and improved quality of life. As an aggregate, the studies did not generally support improvements in physical or functional status. Counter-intuitively, psychological status was found to be poorer in some receiving interventions aimed at improving continuity.

Successful interventions to improve continuity in cancer care will likely be multifaceted, addressing all three types of continuity (RC, MC, IC). This framework shows promise and provides guidance for future study. Studies designed to improve all three types of continuity and impact physical and/or psychological status include Oleske et al. (1988), who demonstrated decreased cancer-related mortality in patients with colorectal, lung or breast cancer receiving an enhanced relational continuity (RC), information continuity (IC) and management continuity (MC) intervention consisting of ONS involvement and continuing cancer education over an information continuity (IC) intervention of continuing cancer education alone. Moore et al. (2002) saw decreases in both symptom distress and resource utilization in lung cancer patients who received an
intervention to target all three types of continuity (RC, IC, and MC) in an intervention consisting of follow-up in an APN led clinic versus conventional medical follow-up. Patients were evaluated more frequently in the APN led clinic versus the conventional follow-up clinic. McCorkle et al. (2009) found improvements in physical and psychological quality of life in women with ovarian cancer following abdominal surgery who received an intervention to improve all three types of continuity (RC, IC, and MC) which consisted of specialized care by an advanced practice nurse (APN) and/or psychiatric consultation liaison nurse (PCLN) over an intervention to improve all three types of continuity (RC, IC and MC) led by a lay research assistant.

McCorkle et al. (2000) demonstrated improvement in symptom distress and decreases in depressive symptoms and enforced social dependency among elderly patients with surgically treated solid tumor cancers assigned to an APN led intervention to improve all three types of continuity (RC, IC, and MC) as compared to patients in the control group. Home visits, telephone contacts, enhanced instructional content, comprehensive clinical assessments and post-surgical management and skills training were key components of the intervention. McLachlan et al. (2001) demonstrated lower depression scores at six months as compared to baseline scores in a group of 450 patients with any type of cancer in any phase of treatment who participated in a nurse-led intervention to improve all three types of continuity (RC, IC, MC). Employing a self-administered questionnaire to determine patients’ cancer-related needs, quality of life and psychosocial status provided information that the nurse coordinator immediately shared with the patients’ provider. The nurse used the information to generate a management plan using psychosocial guidelines formulated by a multidisciplinary group of experts. It
is noteworthy that all these successful interventions designed to improve all three types of continuity of care and improve patient outcomes were led by oncology nurses, APNs or nurses with other specialized training such as PCLN’s.

**Conclusion**

Continuity research in cancer patients is complicated partly because cancer patients are a heterogeneous group. There is wide variation in terms of prognosis, treatment types, side effects, and severity of symptoms among patients with different types of cancer. Continuity interventions may not make a great impact in patients with highly curable cancers that affect younger, healthier patients. Continuity interventions may also be less effective in certain phases of care. Many of the studies in the meta-analysis conducted by Aubin et al. (2012) were conducted in patients in the palliative phase of care that is characterized by rapid physical decline and high levels of psychological distress. Jordhoy et al. (2001), who studied patients who had a malignancy with a life expectancy of two to nine months, noted that their results were consistent with the findings of other RCTs which evaluated the impact of palliative care interventions on patients’ health-related quality of life which also did not find significant improvements in physical or psychosocial aspects of quality of life.

Patients who are facing a lung cancer diagnosis are, in general, elderly with multiple comorbidities. These patients often suffer high levels of anxiety and emotional distress not only because of the high mortality rates associated with their disease, but because they must leave their communities and navigate a system that is completely foreign to them. Patients in cancer care who are disconnected from their primary care providers may not be considered good candidates for curative surgery due to uncontrolled
comorbid conditions and may do worse postoperatively. Maintaining continuity of care between primary care and specialists throughout the cancer trajectory can also provide patients who prove to be incurable with much needed support at the end of life.

Considering the patient perspective is important when designing continuity interventions. Patients take for granted that information continuity and management continuity between PCPs and specialists exist until a disruption occurs, bringing the lack of one or both types of continuity to light (Haggerty et al., 2013). Relational continuity, in the form of a single clinician who will keep them informed, partner with them in their care, help navigate the system, serve as a conduit between all their providers, and make contingency plans, if needed, provides patients with a sense of continuity and security.

Shared care is a well-known model used to improve continuity of care across the primary to specialty care interface. However, a meta-summary of shared care models in patients with chronic diseases found mixed results with no consistent improvements in physical, mental health, psychological, or psychosocial measures including measures of disability and function, hospital admissions, default or participation rates, risk factor modification, or patient satisfaction (Smith et al., 2009). These results are counterintuitive and the methodological qualities of current studies are highly varied with only a few studies of high-quality design. Yet while there is currently insufficient evidence to support the widespread introduction of shared care services, the American Society of Oncology (ASCO) endorses a shared care model to take advantage of the expertise of cancer specialists and PCPs in coordinating cancer care and survivor follow-up.
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Evidence regarding continuity of care in early-stage lung cancer is also limited. Additional exploration of effective interventions to improve continuity of care at the primary to specialty care interface is clearly needed. Aubin et al. (2012) have suggested that any effective interventions will need to be multifaceted; targeting all three types of continuity (RC, IC and MC) and include measured improvement of continuity of care as an outcome. Interventions aimed at improving continuity of care as a singular outcome are not sufficient. Interventions to improve perceived continuity should be evaluated in the context of anxiety or distress as moderators.

Previous studies have attempted to demonstrate that improved continuity correlates with improved physical status, functioning or even survival. However, these outcomes can be a challenge to achieve in lung cancer patients because of the degenerative nature of the disease and high mortality. Outcomes such as decreased distress, improved patient satisfaction, or improved quality of life may be more appropriate measures for lung cancer patients.

Interventions to improve the continuity of care between specialists and PCPs using a shared care framework have the potential to decrease distress in lung cancer patients. Successful shared care models involve separate health care teams making a commitment to work together for the improvement of patient outcomes. This commitment must be supported by enhanced information exchange and the use of a shared management plan that helps to clarify roles. Improving all aspects of continuity (RC, IC and MC) lends structure to the shared care model. Measures of continuity allow for gauging the effect of a shared care intervention. Patients’ perceptions of continuity of care across the primary to specialty care interface can be reliably measured using a
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validated instrument such as the Nijmegen Continuity Questionnaire (NCQ) (Uijen et al., 2011). Though current evidence regarding best practice interventions is lacking, patient care can clearly benefit from enhancing continuity of care. Identifying and incorporating specific interventions into standard practice can improve the lives of patients facing the challenges of living with a lung cancer diagnosis.
References


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Development of an Intervention to Improve Continuity for Kentuckians Facing a Lung Cancer Diagnosis

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Abstract

**Purpose:** The major purpose of this manuscript is to describe the development of an intervention to improve continuity for Kentuckians facing a lung cancer diagnosis using the framework suggested by Aubin et al. (2012). Kentuckians facing a lung cancer diagnosis are at greater risk for care fragmentation due to the complexities associated with the diagnosis, staging and treatment of the disease, and because they must transition from primary to specialty care. A framework for developing an intervention to improve continuity of care for lung cancer patients during the diagnostic, staging, and treatment phase has been proposed as a result of a literature review. However, knowledge gaps remain regarding how to tailor the intervention for optimal effect for Kentuckians facing a lung cancer diagnosis.

**Methods:** To bridge the gap between the current and desired state of continuity, the following topics were explored: inherent and modifiable characteristic of Kentuckians that affect continuity; assessment of continuity-related processes within the Multidisciplinary Lung Cancer Program where many Kentuckians seek care; selection of a valid and reliable instrument to measure continuity in this population; and selection of an outcome that is meaningful to Kentuckians facing a lung cancer diagnosis and is likely to be influenced by a continuity intervention. This information was used to develop and tailor an intervention to improve continuity for Kentuckians facing a lung cancer diagnosis.

**Results:** The intervention will be led by a nurse with specialized oncology experience who will navigate patients through the diagnostic and treatment phases, facilitate information transfer, initiate and update a shared management plan, and serve as a conduit between all providers. The intervention will be administered within the context of
a shared care model that is endorsed by ASCO and has the potential to optimize the efforts of both PCPs and specialists. The Nijmegen Continuity Questionnaire, a valid and reliable instrument for measuring perceived continuity, will be used to measure continuity. Distress, which is pervasive in this population, will serve as the outcome that is meaningful and likely to change because of the continuity intervention.

**Conclusions:** Early implementation of a continuity intervention administered within a shared care model can improve care from the time of initial suspicion of lung cancer through survivorship and end of life care. An intervention to bridge gaps in continuity across the primary to specialty care interface should allow for smoother transitions, better management of comorbid conditions, and provision of supportive care.

**Future Implications:** Future research should include a pilot study to determine the feasibility and effect of incorporating the intervention into standard practice.
Development of an Intervention to Improve Continuity for Kentuckians Facing a Lung Cancer Diagnosis

Kentucky has the highest incidence and mortality rates for lung cancer in the nation (93.1 and 88.3 per 100,000 U.S. population respectively) (U.S. Department of Health and Human Resources, 2014) with the eastern region of the state disproportionately affected (CDC, 2015). Kentuckians facing a lung cancer diagnosis are at greater risk for care fragmentation due to the complexities associated with the diagnosis, staging and treatment of the disease and because they must transition from primary to specialty care.

In the previous paper, a literature review was performed to examine interventions and care models to improve continuity in lung cancer patients during the diagnostic, staging and treatment phases. The literature review revealed there is a paucity of high-quality evidence supporting specific interventions to improve continuity of care in cancer patients. The existing body of research included several successful nurse-led interventions that have improved physical and/or psychosocial outcomes but did not allow one to draw firm conclusions about which interventions or care models were most likely to improve continuity-related outcomes. However, as a conclusion to their meta-analysis, Aubin et al. (2012) made the following recommendations for future research: interventions to improve continuity of care should target all three types of continuity (relational (RC), information (IC) and management (MC)); the study design should include measurement of continuity from the patient’s perspective; and any outcomes should be both meaningful to the study population and sensitive to change as a result of the intervention. Qualitative research revealed that patients may take for granted that
information continuity and management continuity exist until a disruption occurs, bringing the lack of one or both types of continuity to light. However, relational continuity, in the form a single clinician who will keep them informed, partner with them in their care, help navigate the system, serve as a conduit between all their providers, and make contingency plans provides patients with a sense of continuity and security. These findings and recommendations serve as the basis for the development of a tailored continuity intervention. The major purpose of this paper is to describe the development of an intervention to improve continuity for Kentuckians facing a lung cancer diagnosis using the framework suggested by Aubin et al. (2012).

**Problem statement/Background/Literature review**

All Kentuckians facing a lung cancer diagnosis need sufficient support as they transition from primary to specialty care. Though the process of diagnosis, staging and treatment is complex, patients should be comforted emotionally and supported physically through the combined efforts of their primary care and specialty care teams from the very beginning of and throughout their cancer journey. However, this is currently not the case as many patients describe feeling in limbo as they transition from primary to specialty care and attempt to navigate their way through the complex diagnostic, staging and treatment phases of lung cancer.

A framework for developing an intervention to improve continuity of care for lung cancer patients during the diagnostic, staging and treatment phase has been proposed as a result of a literature review. However, knowledge gaps remain regarding how to tailor the intervention for optimal effect for Kentuckians facing a lung cancer diagnosis. To bridge the gap between the current and desired state of continuity, the following
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topics were explored: inherent and modifiable characteristic of Kentuckians that affect continuity; assessment of continuity-related processes within the Multidisciplinary Lung Cancer Program where many Kentuckians seek care; selection of a valid and reliable instrument to measure continuity in this population; and selection of an outcome that is meaningful to Kentuckians facing a lung cancer diagnosis and is likely to be influenced by a continuity intervention. This information was used to develop and tailor an intervention to improve continuity for Kentuckians facing a lung cancer diagnosis.

The intervention to improve continuity is to be implemented in the context of a shared care model. Shared care, in which providers from different specialties co-manage patients, can span the entire cancer trajectory from pre-diagnosis to survivorship. The American Society of Clinical Oncologists (ASCO) endorses a shared care model to take advantage of the expertise of cancer specialists and PCPs in coordinating cancer care and survivor follow-up. A benefit of using a shared care model include that it can be used in any aspect of the cancer journey including the diagnostic phase. In fact, use at the beginning of the cancer journey can improve survivorship care as well as end of life care.

A Cochrane review of the impact of a shared care model to improve continuity across the primary to specialty care interface specified that successful shared models share common elements such as the use of guidelines and shared management plans to help clarify roles, an identified care coordinator (usually a physician or nurse) and enhanced communication mechanisms such as shared medical records or standardized charts that record key medical or psychosocial parameters (Sussman & Baldwin, 2010; Smith, Allwright, & O’Dowd, 2007).
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Background

Continuity has been defined as “how one patient experiences care over time as being coherent and linked: continuity being the result of good information flow, good interpersonal skills and good coordination” (Reid et al., 2002). Three aspects of continuity include: Relational continuity (RC) which refers to an ongoing relationship between a patient and providers; Informational continuity (IC) which refers to the availability and use of information regarding prior events and circumstances to make current care relevant and appropriate and Management Continuity (MC) which refers to the timely and complementary services within a shared management plan (Reid, Haggerty, & McKendry, 2002). Gaps can and frequently do occur in all three types of continuity across the primary to specialty care interface leading to less than optimal outcomes for patients with lung cancer. Bridging gaps in continuity across the primary to specialty care interface can improve three important aspects of care for lung cancer patients during the diagnostic, staging and treatment phase: smoothing transitions and ensuring all providers have current knowledge of a patient’s health status and treatment decisions; identification and management of comorbid conditions which may affect cancer treatments and outcomes; and provision of appropriate supportive care (Sussman & Baldwin, 2010).

Brief System Assessment

The Markey Cancer Center’s Multidisciplinary Lung Cancer Program (MLCP) was established in 1998. The stated goal for the Multidisciplinary Lung Cancer Program is to facilitate a rapid diagnosis and provide innovative treatment; prevention and screening for lung cancer (UK College of Medicine, 2015). The MLCP offers patients
access to multiple oncology specialists who have a broad range of expertise in all aspects of lung cancer and are capable of managing highly complex cases. More than 375 new patients are seen each year. The annual volume is approximately 2000 patient visits. All new lung cancer patients are discussed in a weekly case conference during which time plans for diagnostic and staging procedures, general health assessments and treatment plans are discussed and formulated.

The Markey Cancer Center is designated by the National Cancer Institute (NCI) as a center of excellence. It is the only academic cancer center serving the Central Appalachian population of eastern Kentucky and West Virginia, a distressed region with a lung cancer incidence that is the highest in the United States. The NCI promotes and supports initiatives that strengthen partnerships between NCI cancer centers and community physicians who serve underserved populations (Gage-Bouchard, Rodrigues, Saad-Harfouche, Miller, & Erwin, 2014). As an NCI-designated cancer center, Markey Cancer Center also maintains an affiliate network of cancer treatment centers in Hazard, Frankfort, Georgetown, Cynthiana and Morehead. However, due to the need for specialized equipment and expertise, nearly every patient must travel to the Lexington location for diagnosis, staging and surgical treatment of their lung cancer. There are no affiliate network sites in the far south or eastern regions of the state.

**Continuity and Kentuckians: Inherent Characteristics**

Kentuckians have several inherent characteristics that place them at higher risk for care fragmentation and discontinuities. Kentuckians tend to be more elderly; the proportion of Kentuckians aged 60 and over is growing more rapidly than other segments. The U. S. Census Bureau (2015) estimates that 24.8% of Kentuckians will be
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age 60 or older by the year 2030. Currently, 19.1% are age 60 or older (Administration on Aging, 2015). Kentuckians also are more likely to be economically disadvantaged. Thirty-five of Kentucky’s 120 counties are considered economically distressed (The Appalachian Regional Commission, 2011). In 2015, Kentucky had a per capita income of $38,989 ranking Kentucky 44th in the United States with the average Kentuckian earning only 82% of the national average of $47,669 (U.S. Department of Commerce, 2015). Kentuckians have more chronic health conditions (Meit et al., 2014; Murray et al., 2006; Wingo et al., 2008). Being elderly, having multiple comorbidities, being economically disadvantaged and geographically isolated are factors that are associated with poor health and are more common among people in rural areas (Behringer & Friedell, 2006). All these factors compound the hardships associated with making multiple trips to an urban cancer center for testing and treatment. Onega et al. (2008) conducted a study of rural patients and travel times and found that those living in larger rural towns travel a median of 51 minutes to get to a specialized oncology center while those in smaller isolated towns travel a median of 59 minutes and patients travel a median of 83 and 97 minutes respectively to reach the nearest academic cancer center.

Kentuckians are more likely to be elderly with one or more comorbidities, be economically disadvantaged, and live further from academic cancer centers. Improving continuity between primary and specialty care providers could allow Kentuckians to obtain some care closer to home which would decrease financial hardship associated with travel and the higher copays typically incurred at academic cancer centers.
Modifiable Characteristics

Modifiable characteristics that impact continuity include the fact that Kentuckians have slightly lower educational attainment as compared to the United States. Statistics for 2012 demonstrate that Kentucky ranks number 41 in the United States in terms of the percent of adults 25 to 64 years of age with a high school diploma (86.9% in Kentucky vs. 88% in the United States) (The National Center for Higher Education Management Systems, 2016). Kentuckians also have lower literacy levels. In 2003, the last year for which statistics exist, 12% of all Kentuckians lacked basic prose literacy skills and estimates for some of the poorer counties in Kentucky indicated that up to 21% of Kentuckians lacked basic prose literacy skills (National Center for Education Statistics, 2015). Kentuckians, especially those from Appalachia, may have a distrust of health professionals they are not familiar with and may also have a greater than normal fear of cancer (Behringer et al., 2007). Kentuckians with lung cancer may lack emotional support due to loss of a spouse due to death or divorce. Children often are forced to leave the area to find work. These factors contribute to increased levels of distress as a patient embarks upon the lengthy and complex process of diagnosis and staging of lung cancer. Fostering a good relationship with a trusted PCP can help decrease distress in patients with decreased literacy levels and mitigate the mistrust of health professionals they are unfamiliar with.

Kentuckians facing a lung cancer diagnosis are likely to elderly, economically disadvantaged, geographically isolated, have more chronic conditions, less education, lower health literacy, less emotional support and higher levels of distrust of health care providers and greater than average fears regarding a cancer diagnosis. These
vulnerabilities underscore the need for care that places the patient in a position of security created by bridging the gaps in continuity across the primary to specialty care interface.

**Monitoring Continuity**

Continuity of care is monitored by the MLCP by auditing care access, coordination and communication. The multidisciplinary lung cancer program (MLCP) uses the CG-CAHPS survey (Agency for Healthcare Research and Quality, 2016), which asks patients to report on their experiences with either primary care or specialty care but includes few questions regarding experiences with cross-boundary care. The CG-CAHPS surveys include items related to the three types of continuity (RC, IC and MC). These scores were reviewed and trends related to patient perceptions of continuity are noted. The CG-CAHPS surveys are sent to patients with all types of solid tumors who receive care at the Multidisciplinary Cancer Clinic and are not limited to patients with lung cancer.

CG-CAHPS survey items related to Relational Continuity (RC) include: Ease of obtaining urgent or routine appointments, provider spends enough time with patient, provider listens carefully to patient, provider shows respect for what patient says;

Information Continuity (IC): provider has necessary medical records, provider knows important information regarding your medical history, provider explains things in a way patient understands, provider gives easy to understand instructions, and Management Continuity (MC): Someone follows up with results. CG-CAP scores do not include items exploring management continuity (MC) such as whether patient’s providers (primary care and specialists) work well together or whether the specialist provider shares current information with referring and PCPs in a timely manner.
CG-CAHPs scores showed patients are dissatisfied with the amount of time providers spend with them, the time it takes to get an urgent appointments, the length of time it takes for urgent or non-urgent phone calls to be returned. Patients also reported test results are not always provided in a timely manner. Patients reported that providers have the necessary medical records, knew important information regarding patients’ medical histories but did not explain things in a way patient understands and did not give easy to understand instructions.

Based on the CG-CAHPS scores, there are numerous opportunities for improving all three types of continuity over the primary to specialty care interface which would provide much needed support for patients during the diagnostic, staging and treatment process. Relational continuity (RC) could be greatly improved by providing PCPs with current testing results and treatment plans to review with patients in their offices which is a more familiar setting. PCPs who are well informed about their patient’s status and progress would likely be more willing and prepared to help their patients with urgent issues that occur in between specialist visits. Care integration is dependent upon specialists supplying primary care providers with the necessary information and management plans to make PCP visits productive. Providing PCPs with a list of contacts for the members of the MLCP would encourage PCPs to connect with oncology team members further strengthening RC.

Currently, information exchange between the MLCP and PCPs is complex and dependent upon the efforts of various systems and staff members scattered throughout the academic health care system. A new patient coordinator in the specialists’ offices gathers and organizes records from the PCP or referring provider for all new patients which
likely accounts for patients reporting satisfaction regarding providers having medical records on CG-CAHPS scores. However, there is no corresponding person who ensures that records, including consultations and test results, are transmitted back to the PCP in a timely and coordinated fashion. A web-based portal is available but can be difficult to use for physicians in rural areas of the state where internet connections are slower and not as reliable. Information exchange is further complicated by the fact that the physicians of the MLCP use multiple dictation systems, a combination of electronic and paper records as well as a combination of methods such as faxing and mailing consultation reports to primary providers. By default, consultation notes are sent to the referring provider who may not be the PCP but another specialist such as a pulmonologist. The result is that only consultation reports and office visit reports are sent to referring care providers and may arrive days to weeks after the patient visit. Some reports never arrive for a variety of reasons including failure of the provider to dictate a report, failure on the part of the staff to send the reports or failure of equipment to transmit a report.

Patients receive copious amounts of complex information during an evaluation for lung cancer. Improving information exchange across the specialty to primary care interface would provide PCPs with information needed to review test results, treatment options and the specialists’ office notes with their patients. PCPs who are familiar with the culture, literacy levels and communication styles of their patients are more likely to explain things to patients in a way they understand and provide them with easy to understand instructions.

Treatment plans are discussed each Thursday in the multidisciplinary lung cancer conference. These conferences are not attended by PCPs. Some information regarding the
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management plan is generally included in consultation reports. Often, some of the information regarding diagnosis, staging and treatment plan is missing when notes are sent to the PCP. The management plan is communicated to the patient during an office visit that may take place days to weeks following testing. Currently, management plans are not distributed to the PCP or the patient in written form. Patients are often referred to dieticians, social workers and financial counselors who develop plans for patients. These reports contain valuable information about how patients are coping during the diagnostic, staging and treatment process. These plans are not shared with PCPs unless they access them on the portal. Management continuity is an area with great potential for improving continuity across the specialty care to primary care interface. Providing PCPs with a standardized management plan as well as reports from allied health professionals will provide more substantive information regarding comprehensive management of patients, allowing PCPs to participate more fully in their patients’ care.

**Intervention**

Based on a review of the quantitative and qualitative literature, a multifaceted intervention is proposed to bridge the identified gaps in continuity of care for lung cancer patients. The inherent and modifiable characteristics of Kentuckians facing a lung cancer diagnosis inform this intervention. Additionally, standardized measures were reviewed to perform a brief assessment of continuity within the MLCP. The following description is how the intervention could be incorporated into standard practice.

A specialized oncology nurse, dedicated to ensuring continuity during the diagnostic and treatment phases of the cancer trajectory, will lead the intervention. A major obstacle to improving continuity between specialists and PCPs is the lack of time
and reimbursement for activities that promote continuity such as care coordination, information sharing and integrating care with other healthcare professionals. Due to busy schedules, specialists and PCPs must prioritize their activities. Treating patients, dictating office notes and billing activities generally take precedence. PCPs have difficulty accessing the information they require during the diagnostic period (Cancer Quality Council of Ontario, 2007). Primary care providers and specialists also need assistance with coordinating care and supporting patients during the anxiety provoking diagnostic and treatment process (Gilbert, Green, Lankshear, Burkoski, & Sawka, 2011).

While continuity of care has always been and continues to be associated with professional medical practice, it is also a “fundamental tenet of professional nursing” (Sparbel & Anderson, 2000a; p. 17). Gilbert et al. (2011) conceptualized a model of navigation during the diagnostic phase of cancer care, specifically the time between an initial suspicion of cancer and arrival at a definitive diagnosis. Though there is a paucity of published empirical evidence of the impact of patient navigation during the diagnostic phase, there is evidence that navigators improve the patient experience by providing information when needed and reducing anxiety (Ferrente et al., 2007). From the clinician’s perspective, navigators act as information brokers and care coordinators preparing patients for decision-making and making the diagnostic process more effective and efficient (Gilbert et al., 2011).

Gilbert et al. (2011) advocate for oncology nurses in the role of navigator during the diagnostic phase due to the extensive knowledge, skills and clinical judgment required during this complex phase of cancer care. The benefits of having an oncology nurse in this role include patient assessment, support and preparation, supportive care,
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management of complexity and integration with other clinicians. Management of complexity in the context of patient navigation means managing patients’ physical needs in the context of their cultural, emotional, social and educational situations. Oncology nurses understand the importance of accurate disease staging and other aspects of clinical care placing them in good position to integrate the navigator role with other healthcare professionals, especially physicians (Kneece, 2008). Due to the increasing complexity of certain patient populations and a navigator’s potential involvement in research and planning, some programs employ advanced practice nurses as navigators. One such program involving a multidisciplinary lung cancer clinic determined the navigation role requires a highly skilled nurse practitioner or advance practice nurse with an oncology background (Seek & Hogle, 2007).

Based upon identified gaps in continuity within the MLCP, the intervention will seek to improve all three types of continuity, relational (RC), management (MC) and Information (IC) continuity. To improve RC, a list of names and roles of all multidisciplinary lung cancer team members with contact numbers will be faxed to primary care providers so they will be able to initiate contact with any member of the cancer team. To improve MC, the intervention will include providing PCPs with the Adjuvant Non-Small Cell Lung Cancer Treatment Summary (ASCO, 2009). The template was pilot tested in both academic and community settings and feedback from participants in both settings was used to generate the final template. The treatment plan and summary is intended to enhance physician-to-physician communication and streamline the documentation process. The ASCO template is comprehensive and includes fields for documenting diagnostic and staging information, type of surgical resection and the
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administration of adjuvant chemotherapy, if indicated. These templates allow PCPs to view large amounts of useful data at a glance. The treatment summary will be initiated and updated at key intervals by the oncology nurse in the navigator role. Information from the multidisciplinary lung cancer conference, including diagnosis, staging and treatment plans will be captured and included in the patient’s treatment summary. The summary will be faxed by the nurse to the primary care provider within 72 hours of initiation or update.

To improve IC, physician summaries and reports of consultations and results of testing (pathology reports, radiology reports, general medical assessments such as cardiac stress test and pulmonary function reports) will be transmitted via fax within 72 hours of completion. Results from each completed Distress Thermometer will be faxed to the patient’s primary care provider’s office within 72 hours of completion. To improve all aspects of continuity (RC, MC and IC), the primary care provider’s office will be contacted to obtain notes from any recent visits and these will be placed in the patient’s chart for review by the multidisciplinary lung cancer team prior to patients’ appointments with the specialist provider.

Although Shen et al. (2015) found that PCPs prefer to be communicated with by phone or email, institutional policy and logistics currently favor faxed information. A study by Jefford et al. (2008) found that information faxed to primary care providers is a simple, inexpensive intervention that increases PCP confidence in managing cancer patients.
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Outcomes

Aubin et al. (2012) stated that future continuity research should focus on outcomes that are most sensitive to change. Rural cancer patients experience poorer mental health and greater symptoms of anxiety, depression, distress and emotional functioning than urban cancer patients (Burris & Andrykowski, 2010). Zabora, Brintzenhofeszyoc, Curbow, Hooker and Piantadosi (2001) documented rates of distress across different cancer sites and found patients with lung cancer are at highest risk for experiencing distress. Steinberg et al. (2009) documented high levels of clinically significant distress (> or = to 4 on the Distress Thermometer) in newly diagnosed lung cancer patients. Graves et al. (2007) found that more than half (61.6%) of lung cancer patients experienced distress at clinically significant levels, but only 22.5% indicated interest in receiving help with their distress levels while in the cancer center. Patients, especially those from rural areas, may be reluctant to discuss emotional issues with a specialist they have just met. It is reasonable to expect that distress is an outcome that would be sensitive to change in this population by improving continuity across the primary to specialty care interface. Monitoring for distress in cancer patients is endorsed by the National Comprehensive Cancer Network. Distress can be reliably measured by the Distress Thermometer which has been empirically validated for this purpose (Graves et al., 2007).

Evaluation

Aubin et al. (2012) proposed that future research should include continuity of care as an outcome measure. Until recently there has been a dearth of validated instruments designed to measure multiple dimensions of continuity of care across the primary to
specialty care interface. Uijen et al. (2011) developed the Nijmegen Continuity Questionnaire (NCQ) to measure continuity of care from the patient perspective across primary and secondary care settings. The researchers assessed validity, discriminative ability, and reliability of the NCQ by administering the questionnaire to patients with a chronic disease recruited from general practice (n = 145) and hospital outpatient departments (n = 123) (response rate 76%). Test-retest reliability was analyzed in 172 patients. Principal factor analysis was confirmed for three continuity subscales: personal continuity, care provider knows me; personal continuity, care provider shows commitment; and cross-boundary continuity. Test-retest reliability was high with an intraclass correlation coefficient which varied between 0.71 and 0.82. The authors concluded the NCQ is a valuable tool for identifying problems in continuity of care. The NCQ is practical for the clinic setting as it can be completed in 5 to 10 minutes (Aubin et al., 2012). An in-depth discussion regarding the evaluation of the intervention will take place in paper three.

**Discussion**

It is said that cancer does not discriminate but lung cancer seems to discriminate against Kentuckians in some important ways. Not only does lung cancer affect more people in Kentucky than any other state in the nation; it affects Kentuckians with the fewest personal and economic resources most severely. Kentuckians facing a lung cancer diagnosis are at high risk for care fragmentation due to both inherent and modifiable characteristics. The MLCP is an NCI-designated cancer center that offers Kentuckians facing a lung cancer diagnosis hope in the form of evidence-based treatment and access to clinical trials. The MLCP is committed to strengthening community relationships. An
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intervention to improve continuity between primary and specialty care for Kentuckians facing a lung cancer diagnosis is in keeping with the goals of the MLCP.

Although there is limited research on improving continuity for lung cancer patients in the diagnostic and treatment phases, several nurse led interventions designed to improve all three types of continuity have demonstrated improved patient outcomes including lowering distress which affects a large proportion of lung cancer patients, especially those living in rural areas.

Since the current body of research offers no conclusive evidence regarding interventions to improve continuity of care for lung cancer patients, a review of current continuity-related processes within the MCLP was performed. Patient scores on standardized CG-CAHPs surveys were also reviewed to gain the patient’s perspective on the current state of continuity within the MLCP. The modifiable and inherent characteristics of Kentuckians that could affect continuity have been examined. Based on this information, an intervention was designed to improve all three types of continuity to improve care across the primary to specialty care interface for Kentuckians has been developed.

The intervention will be led by a nurse with specialized oncology experience who will navigate patients through the diagnostic and treatment phases, facilitate information transfer, initiate and update a shared management plan and serve as a conduit between all providers. The intervention will be administered within the context of a shared care model that is endorsed by ASCO and has the potential to optimize the efforts of both PCPs and specialists. A valid and reliable instrument for measuring perceived continuity
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has been identified. Distress, which is pervasive in this population, will serve as the outcome that is meaningful and likely to change because of the continuity intervention.

Conclusion

Early implementation of a shared care intervention can improve care from the time of initial suspicion of cancer through survivorship and end of life care. An intervention to bridge gaps in continuity across the primary to specialty care interface should allow for smoother transitions, better management of comorbid conditions and provision of supportive care. Next steps should include a pilot study to determine the feasibility and effect of incorporating the intervention into standard practice.
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Piloting an Intervention to Improve Continuity in Lung Cancer Patients

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Abstract

**Purpose:** Kentuckians facing a lung cancer diagnosis are at greater risk for care fragmentation due to the complexities associated with the diagnosis, staging and treatment of the disease combined with multiple health disparities such as advanced age, multiple comorbid conditions, low socioeconomic status, geographic isolation, and low literacy levels. Transitioning from primary to specialist care can be especially difficult for these patients. The main purpose of this paper was to determine the feasibility and effect of a nurse-led, multidimensional intervention designed to improve relational (RC), informational (IC), and management continuity (MC) across the primary to secondary care interface, as well as to assess the effect of perceived continuity of care on patient distress levels.

**Methods:** This study included a sample of 40 patients (20 in the comparison group and 20 in the intervention group). The comparison group received usual care, while the intervention group received an intervention targeted at improving all three types of continuity (RC, IC, MC), beginning with the patient’s first visit to a multidisciplinary lung cancer clinic. Patients in both the comparison group and intervention group completed the Distress Thermometer and Nijmegen Continuity Questionnaire at three separate intervals: at the initial appointment with the specialist, at the specialist appointment following diagnosis and staging, and at the post-surgical follow-up appointment.

**Results:** Results indicate that this intervention, along with the natural influence of time, may result in improved perceived continuity scores for the intervention group and in improved relational continuity with the PCP for those receiving the intervention. Distress decreased globally over time independent of group placement but decreased in a more
linear fashion for the intervention group, though the differences between groups did not reach the level of significance. In addition, older age is associated with lower distress levels and may predict distress levels at time one and time two, but this effect disappears at time three.

**Conclusions:** A nurse-led intervention to improve all three types of continuity for Kentuckians facing a lung cancer diagnosis was successfully implemented in a sample of 20 patients at a multidisciplinary lung cancer program at a NCI-designated academic cancer center. This pilot study demonstrated that it is feasible to measure continuity in this population in the clinic setting. This research fills a gap in the literature as the only nurse-led intervention designed to improve three types of continuity across the primary to specialty care interface for lung cancer patients who are in the diagnostic, staging, and treatment phase. This research is also unique in that it uses measured perceived continuity as an outcome.

**Future Implications:** Interventions to improve continuity should be conducted on larger groups of patients with poor prognoses and high levels of distress. Evidence suggests that shared care interventions are appropriate for patient groups who are most likely to benefit, such as patients who are clinically anxious or distressed (Nielsen et al., 2003; Cossich et al., 2004; McCorkle et al., 2009; Johnson et al., 2015). Future studies should also incorporate technological advancements such as teleconferencing between the primary and specialty care teams, and shared electronic medical records such as health portals. Other outcomes in addition to distress, such as resource utilization, that may be sensitive to interventions to improve continuity should also be explored. The role of the
APN as a leader for continuity interventions should be explored by performing a cost/benefit analysis.
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Piloting an Intervention to Improve Continuity in Lung Cancer Patients

Kentuckians facing a lung cancer diagnosis are at greater risk for care fragmentation due to the complexities associated with the diagnosis, staging and treatment of the disease combined with multiple health disparities such as advanced age, multiple comorbid conditions, low socioeconomic status, geographic isolation and low literacy levels. Transitioning from primary to specialist care can be especially difficult for these patients.

The Institute of Medicine (IOM) has advised that members of cancer care teams should coordinate with each other and with primary and specialty care teams to implement patient care plans and deliver comprehensive, efficient, patient-centered care (IOM, 2013). The IOM recommends that PCPs manage comorbid medical conditions, build relationships with patients and oncology team members to improve continuity, elicit patient preferences, and help clarify goals of care for their patients (National Research Council, 2013). Despite these recommendations, discontinuities across the primary to specialty care interface frequently occur due to information exchange problems (Berendsen, de Jong, Meyboom-de Jong, Dekker, & Schuling, 2009; Dudgeon, 2007; Dumont, Dumont, & Turgeon, 2005; Grunfeld, 2006; Haggerty, Reid, Freeman, Starfield, Adair, & McKendry, 2003) and gaps in provider role clarity (Sussman & Baldwin, 2010).

Background

An intervention to improve continuity of care for Kentuckians facing a diagnosis of lung cancer has been proposed in paper two. This intervention was based on current quantitative and qualitative research, characteristics of Kentuckians as they relate to
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continuity and an assessment of continuity-related processes at a large urban academic cancer center where many Kentuckians receive their lung cancer care.

The intervention was implemented as follows: A nurse with specialized oncology training faxed to patients’ PCP offices a list of MLCP contacts, all pertinent reports and distress thermometer results and the shared management plan as previously described. Patients were asked to complete both the Distress Thermometer (see Appendix A) and the Nijmegen Continuity Questionnaire (see Appendix B) at three key time points: at the initial appointment with the specialist, at the treatment planning appointment (following diagnosis and staging), and at the follow-up appointment after surgery. Continuity was measured to identify problem areas in continuity and to evaluate the intervention (Uijen, Schera, Schellevis, Mokkink, & van den Bosch, 2012). Distress levels and patient-perceived continuity were assessed at key intervals to explore relationships between continuity and distress over time in patients who received the intervention.

The main purpose of this paper was to determine the feasibility and effect of a nurse-led, multidimensional intervention designed to improve relational (RC), informational (IC), and management continuity (MC) across the primary to secondary care interface, as well as to assess the effect of perceived continuity of care on patient distress levels.

Methods

IRB approval was obtained through the University of Kentucky’s Institutional Review Board.
Participants

Patients who presented to the Markey Lung Cancer Clinic (MLCL) with a known or suspected diagnosis of early-stage non-small cell lung cancer were invited to participate. Eligible participants were between the ages of 18 and 90, English speaking and had an identified primary care provider at the time of their initial visit. Primary care providers and specialists were not part of this study. Written informed consent was obtained from all participants. Patients were recruited by convenience method. The first twenty patients who met eligibility criteria and were willing to participate were recruited to the comparison group and the subsequent twenty patients who met eligibility criteria and were willing to participate were recruited to the intervention group. Demographic information was collected from all participants.

Comparison Group. The comparison group participants received usual care from their specialist physician and PCP. The current standard was that once a letter was dictated and electronically signed by the specialist, it was faxed to the primary care provider. No other documents, such as testing results or hospital discharge summaries were transmitted unless requested by the primary care provider. Communication frequency and content for standard care were not prescribed by the study.

Intervention Group. The intervention involved a Doctorate of Nursing Practice (DNP) student (also the PI) who acted as coordinator and conduit between the patients’ specialists and PCPs. The DNP student/PI assisted with patient care and information exchange between specialists and PCPs. The DNP student/PI also administered surveys and initiated and updated the treatment summary.
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**Intervention.** The intervention was targeted at improving all three types of continuity (RC, IC, MC) beginning with the patient’s first visit to the MLCC. To improve relational continuity, a list of names and roles and the multidisciplinary lung cancer team members with contact numbers was faxed to primary care providers. To improve informational continuity, physician summaries and reports of consultations and results of testing (pathology reports, radiology reports, general medical assessments such as cardiac stress tests and pulmonary function reports) was faxed to primary care providers within 72 hours of completion. Consultation reports from social workers, Smoking Cessation APRN, dieticians and nurses were faxed within 72 hours of completion. Results from each completed Distress Thermometer were faxed to the patient’s primary care provider’s office within 72 hours of completion. To improve management continuity a standardized summary template, The Adjuvant Non-Small Cell Lung Cancer Treatment Summary (ASCO, 2009) (see Appendix C) was used. This summary was initiated and updated at key intervals by the PI/DNP student and faxed to the PCP within 72 hours. All faxed information included a cover sheet requesting that the information be shown directly to the PCP as soon as possible.

**Study Instruments**

Aubin et al. (2012) recommended future continuity research should include perceived continuity as an outcome. The newly developed Nijmegen Continuity Questionnaire (NCQ) (Uijen et al., 2011) was selected to measure patient-perceived continuity. Validity, discriminative ability, and reliability of the NCQ has been determined and test-retest reliability has confirmed in chronically ill patients, including patients with cancer. The NCQ was developed to examine patients’ perceptions of
continuity across the primary to specialty care interface. The NCQ is practical for the clinic setting as it can be completed in 5 to 10 minutes (Aubin et al., 2012). Items were scored on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), with an additional option to choose ‘?’ (‘I do not know’). Patients answered questions about PCP continuity and specialist continuity as well as cross-boundary continuity. These subscales included items that relate to relational continuity (RC), informational continuity (IC) and management continuity (MC).

An adaptation of the Distress Thermometer (Graves et al., 2007) was used to measure distress levels. Distress is more prevalent in new and follow-up lung cancer patients than patients with other types of cancer (Carlson, Angen, & Cullum, 2004; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). The Distress Thermometer is a visual-analog tool developed to screen for distress in cancer patients by asking patients to rate their level of distress on a scale of 0 to 10. Sensitivity, specificity, and cut-off score have been previously established with a score of 4 or above indicating clinically significant distress (Jacobsen, Donovan, Trask, Fleishman, Zabora, Baker, & Holland, 2005).

The Distress Thermometer (DT) and the Nijmegen Continuity Questionnaire (NCQ) were administered at three intervals: 1.) at the initial appointment, 2.) at the treatment planning appointment following diagnosis and staging and 3.) at the postsurgical follow-up.

Sample Size

A sample of 40 patients with known or suspected early stage lung cancer (20 patients in each group) was deemed appropriate for this pilot study. Patients were
recruited by convenience method beginning with the comparison group. Patients found to have benign disease or advanced disease during the diagnostic and staging process were excluded from analysis and another patient was recruited. Once 20 patients were recruited into the comparison group, 20 patients were recruited into the intervention group in the manner previously described. Participants were not blinded because the intervention group was encouraged to call their primary care providers with any issue they felt appropriate for that setting and were assured that current information should be available to their providers. Each participant was aware of which group they were recruited.

Results

Descriptive Statistics

The final sample consisted of 40 participants, 55% of which were female (n = 22; male: n = 18, 45%), with an average age of 64.48 years (SD = 9.89). A majority of participants were Caucasian (n = 38, 95%) and lived in rural locations (n = 25, 62%). All patients had suspected or known lung cancer. Many had comorbid conditions (n = 28, 70%), and most reported having a supportive partner (n = 37, 92.5%). All frequencies and percentages are presented in Table 3.1.

Summary of the Results

Detailed Analysis

Research Question One: What is the relationship between the comparison and intervention group’s perceived continuity scores at key intervals (time 1: first specialist consulting; time two: treatment planning; time 3: specialist follow-up after surgical treatment)?
To address this question, a series of Pearson’s correlations were run. In this analysis, distress and continuity were assessed for correlations at each of the three key time intervals, which resulted in three Pearson correlation analyses. Results of the Pearson’s correlations suggested that at each interval, continuity and distress were not significantly correlated (i.e., \( p > .05 \) for all). The Pearson correlation coefficients are presented in Table 3.2.

**Research Question Two: Are there significant differences in continuity and distress scores between the comparison group and the intervention group at the key intervals?**

To address this research question, two 2x3 mixed ANOVAs were performed. The advantage of the mixed ANOVA is in its ability to assess multiple groups’ respective changes in a continuous variable over time (Stevens, 2009). In these mixed ANOVAs, the variable of time was included, and had three levels; similarly, group placement was also included in the model and had two levels.

The results of the first 2x3 mixed ANOVA were posed to examine differences based on the group (i.e., intervention versus comparison) and key interval when continuity scores were measured indicating that there is a significant main effect of time for the continuity score (\( F(2, 76) = 24.55, p < .001, \eta^2_{\text{partial}} = .39 \)), and a significant interaction between time and group placement, \( F(2, 76) = 5.61, p < .001, \eta^2_{\text{partial}} = .19 \), but no significant main effect for type of group itself, \( F(1, 38) = .1, p = .360, \eta^2_{\text{partial}} = .02 \).

This suggests that while there were significant differences between the two groups at each time, this difference cannot be accounted for by the intervention alone; instead, the effect of time must also act on the intervention group to produce a change. This provides
evidence that the comparison and intervention group were similar prior to the intervention, indicating there was no initial tendency for one group to score naturally higher or lower than the other. Pairwise comparisons and examination of the means revealed that continuity scores significantly increased between Times 1 and 2 ($p < .001$) as well as between Times 1 and 3 ($p < .001$), but that there was not a significant increase between Times 2 and 3 ($p = .639$). The results of this ANOVA are presented in Table 3.3 and illustrated in Figure 3.1.

The results of the second mixed ANOVA to assess differences in distress levels based on group placement and time indicated that there is a significant main effect of time overall on distress scores, $F(2, 76) = 11.24$, $p = <.001$, $\eta^2_{\text{partial}} = .23$. However, there was no evidence for a statistically significant effect for the group placement variable, $F(1, 38) = 0.00$, $p = .963$, $\eta^2_{\text{partial}} = .00$, indicating that both groups exhibited statistically similar changes in distress over time. There was also no significant interaction between group placement and the effect of time ($F(2, 76) = 1.62$, $p = .205$, $\eta^2_{\text{partial}} = .04$), suggesting that changes in distress were global and were not significantly dependent upon the intervention. Pairwise comparisons of distress at each of the key intervals indicated that distress significantly decreased between times 1 and 2 ($p < .001$), times 1 and 3 ($p = .001$), but did not significantly decrease between times 2 and 3 ($p = .929$). The results of both ANOVAs are presented in Table 3.4.

**Research Question Three:** What key trends emerge in the comparison and intervention groups when questions from the Nijmegen Continuity Questionnaire (NCQ) are analyzed using the following categories: relational, informational, and management continuity?
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To assess this research question, a MANOVA between type of group and the subscales of continuity scores was proposed. However, for this MANOVA to be used accurately, the four subscales of continuity (i.e., relational with PCP, relational with specialist, informational, and management) must be significantly correlated such that they all measure an overarching concept (Stevens, 2009). For these subscales, the overall concept is perceived continuity, and all four can be considered to measure this concept if they are significantly correlated. To determine if these three subscales were correlated, a series of three correlation matrices were created, where the four subscales of continuity were assessed for correlations at time one, time two, and time three. Results showed no significant correlation between these subscales of continuity at any of the three key intervals (i.e., $p > .05$ for all). Based on these findings, the MANOVA could not be used, as the MANOVA relies on the assumption that any dependent variables in the model must be correlated (Stevens, 2009). In place of this MANOVA, a series of ANOVAs were conducted, as the ANOVA can be conducted on each individual dependent variable without the assumption that these variables are correlated.

Similar to the analysis of research question two, these ANOVAs were posed to examine differences based on time (i.e., three key intervals) and group placement (i.e., intervention and comparison). Based on these parameters, the four analyses were conducted as 2x3 mixed ANOVAs. Results of this series of ANOVAs showed differences based on the interaction of time and the intervention for relational continuity with the PCP ($F(2,76) = 3.78, p = .027$), and time-based differences in relational continuity with the specialist ($F(2,76) = 20.88, p < .001$), regardless of whether they were
exposed to the intervention or not. No other statistically significant changes were identified. These outcomes are shown in Table 3.5.

After identifying which variables were significantly different based either on time or a combination of time and the intervention, these differences were assessed for directionality. For relational continuity with the PCP members of the intervention group saw a consistent increase, while those in the comparison group saw a subtle increase followed by a minor decrease (see Figure 3.3). For relational continuity with the specialist, both the intervention and comparison groups saw an increase in this measure over time. As shown in Figure 3.4, these increases were similar and did not depend on exposure to the intervention. As indicated in Table 3.5 above, these were the only significant differences identified.

**Research Question Four: Are there significant differences between perceived continuity scores and distress scores associated with demographic information (sex, age, comorbidity, presence of a supportive partner, location, and educational levels)?**

To assess these possible differences, a series of multiple linear regressions were performed with the demographic factors predicting continuity scores and distress scores at each of the key intervals. This method resulted in three sets of analyses, with one set for each dependent variable. These three sets of analyses are listed as ordered by each dependent variable below.

**Continuity.** The results of the three regressions predicting continuity scores were not significant at any of the three key intervals, (Time 1: \( F(6, 33) = 0.58, p =.744, R^2 = 0.10 \); Time 2: \( F(6, 33) = 0.15, p =.987, R^2 = 0.03 \); Time 3: \( F(6, 33) = 1.18, p =.342, R^2 = 0.25 \).
0.18), indicating that the demographics of the participants did not significantly predict perceived continuity at any time. As overall significance was not found in the model, the individual predictors were not examined for any regression on continuity measurements.

**Distress.** The results of the regression predicting distress scores was significant at time one \(F(6, 33) = 20.40, p = .019, R^2 = 0.35\), indicating that at the time of first specialist consultation, the demographics of the participants significantly predicted their level of distress. The coefficient of determination \(R^2\) value suggests that demographics accounts for up to 35\% of the variability in distress levels at the time of initial consultation. Examination of the coefficients revealed that only age was an individually significant predictor of distress \(B = -0.17, p = .001\); for each 1-year increase in age, participants’ initial levels of distress tended to be 0.17 units lower. Table 3.6 presents the coefficients of the individual predictors.

The results of the regression predicting distress scores at time two was also significant, \(F(6, 33) = 3.14, p < .05, R^2 = .37\), suggesting that demographic factors significantly predicted distress at the time of treatment planning, explaining up to 36\% of the variability in distress. Examination of the coefficients showed that again, age was the only individually significant predictor of distress \(B = -0.13, p < .01\). This analysis indicated that each year increase in age corresponded with a distress level 0.13 units lower at the time of treatment planning. Table 3.7 presents the coefficients of the individual predictors for this regression.

The results of the regression predicting distress scores at time 3 was not significant, \(F(6,33) = 1.18, p = .342, R^2 = .18\), indicating that the demographics of the participants did not significantly predict their level of distress at the time of the follow-
up. As overall significance was not found in the model, the individual predictors were not examined.

**Discussion**

Prior to the implementation of the pilot, the researcher hypothesized that continuity and distress would decrease over time in both the comparison and intervention groups but the intervention group would experience higher levels of perceived continuity and lower levels of distress than the comparison group. Other hypotheses included that experienced relational, information and management continuity would be reflected in perceived continuity scores and that other trends may emerge when demographic information was examined in relationship to perceived continuity and levels of distress.

**Research Question One:** What is the relationship between the comparison and intervention group’s perceived continuity scores and distress scores at key intervals (time 1: first specialist consulting; time two: treatment planning; time 3: specialist follow-up after surgical treatment)?

A series of Pearson’s correlations were not significant indicating there was no relationship between perceived continuity scores and distress levels at any of the key intervals. These findings were unexpected but may be because patients assume continuity between PCPs and specialists until proven otherwise, and because a multitude of factors, other than perceived continuity, affect distress levels in lung cancer patients.

**Research Question Two:** Are there significant differences in continuity and distress scores between the comparison group and the intervention group at the key intervals?
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To determine if there were differences in continuity scores and distress scores based on time and group placement (i.e., intervention vs. comparison), two 2x3 mixed ANOVAs were performed. The first of these ANOVAs indicated that there is a main effect of time and a significant interaction between time and group type influencing continuity scores with the intervention group having higher continuity scores.

This result supports the original hypothesis that both groups would experience increased perceived continuity over time, but the intervention group would have higher continuity scores than the comparison group.

The second of these ANOVAs indicated the presence of an effect of time on distress, where both groups experienced a similar decrease in distress over time, regardless of their group placement as an intervention or comparison group participant.

These results mirror observations in clinical practice. Patients typically present at the initial specialist visit (time interval 1) with high levels of anxiety. However, once patients are diagnosed and staged and have a treatment plan (time interval 2), distress levels decline and patients generally maintain lower anxiety levels through the postoperative visit (time interval 3).

Although it does not reach the level of significance, it is noteworthy that distress levels in the intervention group declined in a more linear fashion than in the comparison group. This might be because continuity interventions seem to be more effective in clinically anxious or distressed patients (Nielsen, Palshof, Mainz, Jensen, & Olesen, 2003; Cossich et al., 2004; McCorkle et al., 2009; Johnson et al., 2015). In a study published after this pilot, Johnson et al. (2015) demonstrated the effect of a shared care intervention was more evident in a subgroup of clinically anxious cancer patients.
Research Question Three: What key trends emerged in the comparison and intervention groups when questions from the Nijmegen Continuity Questionnaire (NCQ) were analyzed using the following categories: relational (RC), information (IC) and management (MC)?

To examine whether or not there was a significant difference between type of groups and the subscales (relational continuity with the PCP, relational continuity with the specialist, information continuity and management continuity) of the Nijmegen Continuity Questionnaire (NCQ), a series of ANOVAs were conducted. These ANOVAs identified differences in relational continuity only, where both relational continuity with the PCP and specialist increased over time. However, relational continuity with the PCP changed based on the intervention’s effect over time, while the relational continuity with the specialist increased globally regardless of group placement.

An increase in relational continuity with the PCP in the intervention group was expected as was an increase in relational continuity with the specialist. It appears that only relational continuity with the PCP is influenced by the intervention. Relational continuity with the specialist increases over time regardless of group placement. The fact that information and management continuity were not associated with an increase in perceived continuity supports the research of Haggerty et al. (2013) who found patients experience continuity of care as a feeling of security and confidence rather than seamlessness and that coordination and information transfer is assumed until proven otherwise.
Research Question Four: Are there significant differences between perceived continuity scores and distress scores associated with demographic information (sex, age, comorbidity, presence of a supportive partner or rural or urban location)?

A series of regressions were performed to assess whether or not participant’s demographics information (age, sex, urban or rural location, presence of one or more comorbidity) predicted their levels of perceived continuity and distress at each point in time. Demographic information did not predict participants’ perceived continuity at any point in time but did predict participants’ distress at times 1 and 2. Of the demographic characteristics, age was the only individually significant predictor of these distress scores, where older participants tended to have lower distress scores.

These results are in keeping with findings by Graves et al. (2007) who found that younger age was associated with higher levels of distress while older age is associated with lower levels of distress.

In summary, there were no differences between perceived continuity scores and distress at any of the key time points but that may be because patients assume continuity until proven otherwise, and distress is multifactorial. As hypothesized, the results do indicate a main effect of time and a significant interaction of group placement influencing continuity scores with the intervention group having higher continuity scores. The fact that distress scores decreased globally regardless of group placement was not expected but may be due to the small number of participants in this study. It is noteworthy that distress scores did decrease in a more linear fashion in the intervention group. This would seem to support research that suggests continuity interventions are more effective in clinically anxious or distressed patients. The results also indicate an interaction of time...
and group placement for increased relational continuity with the PCP while relational continuity increased globally regardless of group placement over time with the specialist. This would seem to indicate that patients did interact with their PCPs and did benefit from the enhanced information exchange. Finally, demographic information did not predict participant’s perceived continuity at any point in time, but did predict participant’s distress at times 1 and 2. Distress scores significantly decreased between Times 1 and 2 and between Times 1 and 3 but there was not a significant increase between Times 2 and 3. This may be because distress scores are typically high at the initial visit (time 1) but decrease at time 2 because patients have completed the diagnostic and staging process and know they are likely to have early stage lung cancer for which surgery may produce a favorable long term prognosis. Of the demographic characteristics, age was the only individually significant predictor of these distress scores, where older participants tended to have lower distress scores.

Limitations

The main limitation of this study is small sample size. The generalizability of this study is also limited because the population is homogenous, consisting entirely of early stage lung cancer patients. However, a criticism of other studies has been that previous study populations have been, perhaps, too heterogeneous by including patients with cancers with very different prognoses or patients in different stages of disease. Researchers have hypothesized that the effects of improved continuity might be more evident in a group of cancer patients with a poor prognosis. Another limitation is lack of blinding though this was intentional because the researcher decided patients in the intervention group should benefit from the improved information transfer from the
specialist to primary care provider. Patients were instructed to contact their primary care provider for any issues they felt appropriate to that setting with the knowledge that their provider would have current information regarding their progress along the diagnostic, staging and treatment trajectory.

**Implications for practice**

An APN should lead initiatives to improve continuity across the primary to specialty care interface during the diagnostic and treatment phases of lung cancer due to the extensive knowledge, skills and clinical judgment required during this complex phase of cancer care. An APN is an expert in patient assessment, patient support and preparation, supportive care and management of complexity and integration with other clinicians. An APN can incorporate patients’ physical, cultural, emotional, social and educational needs into the care plan to integrate care with the patient’s PCP. An APN is also prepared by her education to participate in research initiatives. Continuity initiatives should begin as early as possible, at the time lung cancer is suspected if possible. An APN should initiate and update the shared management plan. This plan can be passed on to the PCP as well as to the medical oncologist and radiation therapist and ultimately to the survivorship APRN as appropriate. While it is possible and perhaps necessary to delegate some of the tasks associated with information transfer, the APN should be ultimately responsible for the timely transfer of information to the PCP’s office. An APN is also in prime position to partner with information technology to incorporate the shared management plan into the electronic medical record (EMR) and assist in developing methods of automated information transfer. APNs should also evaluate the effectiveness
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of continuity interventions and ensure routine monitoring of continuity across the primary to specialty care interface.

**Future Research**

Interventions to improve continuity should be conducted on larger groups of patients with poor prognoses and high levels of distress. Evidence suggests that shared care interventions are appropriate for patient groups who are most likely to benefit such as patients who are clinically anxious or distressed. (Nielsen et al., 2003; Cossich et al., 2004; McCorkle et al., 2009; Johnson et al., 2015). Future studies should also incorporate technological advancements such as teleconferencing between the primary and specialty care teams and shared electronic medical records such as health portals. Other outcomes in addition to distress, such as resource utilization, that may be sensitive to interventions to improve continuity should also be explored. Randomization and blinding would also increase the quality of future studies. The role of the APN as a leader for continuity interventions should be explored by performing a cost/benefit analysis.

**Conclusion**

A nurse-led intervention to improve all three types of continuity for Kentuckians facing a lung cancer diagnosis was successfully implemented in a sample of 20 patients at a Multidisciplinary lung cancer program at a NCI-designated academic cancer center. This intervention, along with the natural influence of time, resulted in improved perceived continuity scores for the intervention group and in improved relational continuity with the PCP for those receiving the intervention. Distress decreased globally over time independent of group placement but decreased in a more linear fashion for the intervention group though the differences between groups did not reach the level of
significance. In addition, older age was associated with lower distress levels, and may predict distress levels at time one and time two, but this effect disappears at time three.

This research fills a gap in the literature as the only nurse led intervention designed to improve three types of continuity across the primary to specialty care interface for lung cancer patients who are in the diagnostic, staging and treatment phase. This research is also unique in that it uses measured perceived continuity as an outcome.

This pilot study demonstrated that it is feasible to measure continuity in this population in the clinic setting. Keeping up with the enhanced information transfer and updating the treatment summaries did prove challenging in addition to assessing patients in clinic, coordinating care and telephone triage. However, by incorporating the intervention into the workflows of the clinic, many tasks could be automated through IT or delegated to unlicensed personnel. An APN should maintain responsibility and accountability for initiating and updating the treatment summary and the timely transfer of information to PCPs offices.
Table 3.1 Frequencies and Percentages for Demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
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</tr>
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<td>Female</td>
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</tr>
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<tr>
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<tr>
<td>Rural</td>
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<td></td>
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</tr>
<tr>
<td>No</td>
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<tr>
<td>No</td>
<td>28</td>
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Table 3.2  Pearson’s Correlation Coefficients ($r_p$) between Continuity and Distress at Key Intervals.

<table>
<thead>
<tr>
<th></th>
<th>Continuity Time 1</th>
<th>Continuity Time 2</th>
<th>Continuity Time 3</th>
</tr>
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<td>--</td>
<td>-.01</td>
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<td>Distress Time 3</td>
<td>--</td>
<td>--</td>
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Note: * denotes significance at the .05 level. ** denotes significance at the .01 level.
Table 3.3 ANOVA of Continuity Score Based on Group Placement and Time at The Key Intervals

<table>
<thead>
<tr>
<th>Effect</th>
<th>SS</th>
<th>df</th>
<th>Error df</th>
<th>F</th>
<th>p</th>
<th>$\eta^2_{\text{partial}}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td>7.17</td>
<td>2</td>
<td>76</td>
<td>24.55</td>
<td>&lt;.001</td>
<td>.39</td>
</tr>
<tr>
<td>Time * Group</td>
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<td>2</td>
<td>76</td>
<td>5.61</td>
<td>.005</td>
<td>.13</td>
</tr>
<tr>
<td>Group</td>
<td>0.54</td>
<td>1</td>
<td>38</td>
<td>0.86</td>
<td>.360</td>
<td>.02</td>
</tr>
</tbody>
</table>
Table 3.4  ANOVA of Distress Scores Based on Group Placement and Time at Key Intervals

<table>
<thead>
<tr>
<th>Effect</th>
<th>SS</th>
<th>df</th>
<th>Error df</th>
<th>F</th>
<th>p</th>
<th>$\eta^2_{partial}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td>89.02</td>
<td>2.00</td>
<td>76.00</td>
<td>11.24</td>
<td>&lt;.001</td>
<td>.23</td>
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<tr>
<td>Time * Group</td>
<td>12.82</td>
<td>2.00</td>
<td>76.00</td>
<td>1.62</td>
<td>.205</td>
<td>.04</td>
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<tr>
<td>Group</td>
<td>0.03</td>
<td>1</td>
<td>38</td>
<td>0.00</td>
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Table 3.5  Results of ANOVAs Assessing Differences on Subscales of Continuity by Time and Group.

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<th>Source</th>
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<th>MS</th>
<th>F</th>
<th>p</th>
</tr>
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<tbody>
<tr>
<td>ANOVA 1: PCP relational continuity</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>0.12</td>
<td>0.06</td>
<td>0.60</td>
<td>.550</td>
</tr>
<tr>
<td>Time*intervention</td>
<td>0.73</td>
<td>0.37</td>
<td>3.78</td>
<td>.027</td>
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<tr>
<td>ANOVA 2: Specialist relational continuity</td>
<td>19.32</td>
<td>9.66</td>
<td>20.88</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Time</td>
<td>1.95</td>
<td>0.98</td>
<td>2.11</td>
<td>.129</td>
</tr>
<tr>
<td>Time*intervention</td>
<td>1.64</td>
<td>0.82</td>
<td>1.44</td>
<td>.255</td>
</tr>
<tr>
<td>ANOVA 3: Informational continuity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>1.64</td>
<td>0.82</td>
<td>1.44</td>
<td>.255</td>
</tr>
<tr>
<td>Time*intervention</td>
<td>1.88</td>
<td>0.94</td>
<td>2.69</td>
<td>.098</td>
</tr>
<tr>
<td>ANOVA 4: Management continuity</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>0.55</td>
<td>0.27</td>
<td>0.78</td>
<td>.474</td>
</tr>
<tr>
<td>Time*intervention</td>
<td>1.88</td>
<td>0.94</td>
<td>2.69</td>
<td>.098</td>
</tr>
</tbody>
</table>
Table 3.6  Coefficients of The Regression with Demographics Predicting Distress at Time One

<table>
<thead>
<tr>
<th>Model</th>
<th>B</th>
<th>SE</th>
<th>β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-0.17</td>
<td>0.05</td>
<td>-.55</td>
<td>-3.52</td>
<td>.001</td>
</tr>
<tr>
<td>Sex</td>
<td>1.32</td>
<td>0.86</td>
<td>.22</td>
<td>1.53</td>
<td>.136</td>
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<td>Ethnicity</td>
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<td>2.20</td>
<td>-.08</td>
<td>-0.47</td>
<td>.644</td>
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<td>Location</td>
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<td>0.98</td>
<td>.12</td>
<td>0.75</td>
<td>.459</td>
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<tr>
<td>Supportive partner</td>
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<td>1.67</td>
<td>.10</td>
<td>0.68</td>
<td>.503</td>
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<td>Comorbidity</td>
<td>0.95</td>
<td>0.94</td>
<td>.15</td>
<td>1.01</td>
<td>.318</td>
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</table>
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Table 3.7 Coefficients of The Regression with Demographics Predicting Distress at Time Two

<table>
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<tr>
<th>Model</th>
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<th>SE</th>
<th>β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
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<td>0.04</td>
<td>-.50</td>
<td>-3.20</td>
<td>.003</td>
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<tr>
<td>Sex</td>
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<td>0.73</td>
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<td>1.91</td>
<td>.065</td>
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<td>Ethnicity</td>
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<td>1.86</td>
<td>-.01</td>
<td>-0.08</td>
<td>.935</td>
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<tr>
<td>Location</td>
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<td>0.83</td>
<td>-.05</td>
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</tr>
<tr>
<td>Supportive partner</td>
<td>0.06</td>
<td>1.41</td>
<td>.01</td>
<td>0.04</td>
<td>.969</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>0.08</td>
<td>0.80</td>
<td>.02</td>
<td>0.10</td>
<td>.919</td>
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</table>
Figure 3.1. Comparison and intervention group continuity scores at key intervals.
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Figure 3.2. Comparison and intervention group distress scores at key intervals.
Figure 3.3. Changes in relational continuity with PCP
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Figure 3.4. Changes in relational continuity with specialist.
References


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Conclusion

This practice inquiry project identified that Kentuckians facing a lung cancer diagnosis are at high risk for care fragmentation as they transition from primary to specialty care during the diagnostic, staging and treatment phases of the disease. This project also identified a lack of high-quality studies regarding interventions to improve continuity in the current literature. Qualitative research indicates that patients experience continuity as security and confidence rather than seamlessness. Relational continuity in the form a single clinician who keeps them informed, partners with them in their care, helps navigate the system, serves as conduit between all their providers, and makes contingency plans provides patients with a sense of continuity and security. A framework was developed from the literature as the basis for development of an intervention to improve continuity of care for this population. The characteristics of Kentuckians were examined and used to tailor the intervention to their needs. Continuity-related characteristics of the cancer center were also evaluated and informed development of the intervention. The intervention targeted all three forms of continuity: RC, IC, and MC.

The Nijmegen Continuity Questionnaire was selected to measure perceived continuity in this population. Distress was selected as a patient-centered outcome that is meaningful to this population and is likely to change due to the intervention. Once developed, the intervention was piloted in a group of 40 patients at an NCI-designated academic cancer center and the results were analyzed.

The knowledge from this project will be presented to administration to request one FTE for an Advanced Practice Nurse (APN) to incorporate the continuity intervention into standard practice. Knowledge from this project will be submitted to
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journals and conferences. This project inquiry project was carried out to satisfy the requirements of DNP program but also to improve the care of Kentuckians who are facing a lung cancer diagnosis. Although this was a small pilot project, the results are encouraging and the knowledge gained regarding the application of principles of evidenced based practices have contributed to an expanding skill set and capacity for improving outcomes for larger populations in the future.
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Appendix A

Date: ______________________

As part of our attempt to care for your total needs, we would like you to fill out the following questionnaire so that we may better approach your healthcare. We believe that all aspects of your life are important and have an effect on the way you feel.

During the past week, how distressed have you been? Check the causes of your distress (all that apply):

(Please shade in the thermometer)

<table>
<thead>
<tr>
<th>Practical Problems</th>
<th>Physical Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing</td>
<td>Pain</td>
</tr>
<tr>
<td>Insurance</td>
<td>Nausea/vomiting</td>
</tr>
<tr>
<td>Work/school</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Transportation</td>
<td>Sleep/insomnia</td>
</tr>
<tr>
<td>Child care</td>
<td>Getting around</td>
</tr>
<tr>
<td></td>
<td>Bathing/dressing</td>
</tr>
<tr>
<td></td>
<td>Breathing</td>
</tr>
<tr>
<td></td>
<td>Mouth sores/swallowing</td>
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<td>Family Problems</td>
<td>Loss of appetite</td>
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<tr>
<td>Partner</td>
<td>Talking</td>
</tr>
<tr>
<td>Children</td>
<td>Constipation/diarrhea</td>
</tr>
<tr>
<td>Other:</td>
<td>Changes in urination</td>
</tr>
<tr>
<td></td>
<td>Tingling hands/feet</td>
</tr>
<tr>
<td>Emotional Problems</td>
<td>Sexual problems</td>
</tr>
<tr>
<td>Depression</td>
<td>Skin dry/itchy</td>
</tr>
<tr>
<td>Nervousness/anxiety</td>
<td>Swollen arms/legs</td>
</tr>
<tr>
<td>Adjusting to my illness</td>
<td></td>
</tr>
<tr>
<td>Isolation/feeling alone</td>
<td></td>
</tr>
<tr>
<td>Boredom</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Spiritual/Religious Concerns</td>
<td>Cognitive Problems</td>
</tr>
<tr>
<td>Relating to God</td>
<td>Forgetfulness</td>
</tr>
<tr>
<td>Loss of faith</td>
<td>Seeing/hearing things</td>
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<tr>
<td>Facing my mortality</td>
<td>Feeling confused</td>
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<tr>
<td>Loss of my sense of purpose</td>
<td>Poor thinking</td>
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<td>Information Concerns</td>
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<td>Lack of information about my diagnosis</td>
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<tr>
<td>Lack of information about my treatment</td>
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<tr>
<td>Lack of information about alternative therapy choices</td>
<td></td>
</tr>
<tr>
<td>Lack of information about maintaining fitness</td>
<td></td>
</tr>
</tbody>
</table>

1. Do you wish to get help for any of the problems listed above?  
2. If yes, which of these is/are most distressing?

3. If we cannot follow-up with you in clinic today, what is the best way to contact you?

STAFF USE ONLY:
Reviewed by: __________________________
Referral Made to:  
- S.O.S. Committee
- Research Protocol
- Pain Team
- Hospice
- Integrated Medicine
- Lymphedema Clinic
- Other: __________________________

Date: __________________________
Referral Made to:  
- Patient Education
- Psychiatry
- Social Work
- SMPC
- PT
- OT

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Appendix B

Supplemental Material (Online Only)

**Appendix: Nijmegen Continuity Questionnaire (NCQ)**

# Nijmegen Continuity Questionnaire

**Questionnaire instructions**

We are interested in your experiences with the care providers that you contacted in the last 12 months.

This questionnaire includes 28 statements, and will take about 5-10 minutes to complete.

There are no right or wrong answers. Your honest opinion is what counts.

For each statement, choose the answer that best describes your opinion.

All the information you provide will be kept completely confidential. Your answers will not be passed on to your care providers or others.
1. The following statements are about your (own) general practitioner

*If you did not contact a general practitioner in the last year, please go on to the next section.*

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>I know my general practitioner very well</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b</td>
<td>My general practitioner knows my medical history very well</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c</td>
<td>My general practitioner always knows very well what he/she did previously</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d</td>
<td>My general practitioner knows my familial circumstances very well</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>e</td>
<td>My general practitioner knows my daily activities very well</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>f</td>
<td>My general practitioner contacts me if it is needed, I do not have to ask</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>g</td>
<td>My general practitioner knows very well what I believe is important in my care</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>h</td>
<td>My general practitioner keeps in contact sufficiently when I see other care providers</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
2. The following statements are about the cooperation between care providers in general practice (e.g., between general practitioner and nurse practitioner or between several general practitioners).

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>These care providers transfer information very well to each other</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>b</td>
<td>These care providers work together very well</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>c</td>
<td>The care of these care providers is very well connected</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>d</td>
<td>These care providers always know very well from each other what they do</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
3. The following statements are about your (most important) specialist

If you did not contact a specialist in the last year, please go on to the next section.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a  I know this care provider very well</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b  This care provider knows my medical history very well</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c  This care provider always knows very well what he/she did previously</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d  This care provider knows my familial circumstances very well</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e  This care provider knows my daily activities very well</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f  This care provider contacts me if it is needed, I do not have to ask</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g  This care provider knows very well what I believe is important in my care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h  This care provider keeps in contact sufficiently when I see other care providers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 4. The following statements are about the cooperation between care providers in hospital (e.g., between several specialists or between specialist and nurse)

<table>
<thead>
<tr>
<th>a</th>
<th>These care providers transfer information very well to each other</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>?</th>
</tr>
</thead>
<tbody>
<tr>
<td>b</td>
<td>These care providers work together very well</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly disagree</td>
<td>?</td>
</tr>
<tr>
<td>c</td>
<td>The care of these care providers is very well connected</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly disagree</td>
<td>?</td>
</tr>
<tr>
<td>d</td>
<td>These care providers always know very well from each other what they do</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly disagree</td>
<td>?</td>
</tr>
</tbody>
</table>

If this section does not apply to you, please go on to the next section.

### 5. The following statements are about the cooperation between your general practitioner and your specialist.

<table>
<thead>
<tr>
<th>a</th>
<th>These care providers transfer information very well to each other</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>?</th>
</tr>
</thead>
<tbody>
<tr>
<td>b</td>
<td>These care providers work together very well</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly disagree</td>
<td>?</td>
</tr>
<tr>
<td>c</td>
<td>The care of these care providers is very well connected</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly disagree</td>
<td>?</td>
</tr>
<tr>
<td>d</td>
<td>These care providers always know very well from each other what they do</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neutral</td>
<td>Disagree</td>
<td>Strongly disagree</td>
<td>?</td>
</tr>
</tbody>
</table>
PILOTHING AN INTERVENTION TO IMPROVE CONTINUITY

Any comments/remarks:

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........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
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........................................................................................................................................

Thank you for your help!
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Appendix C

Adjuvant Non Small Cell Lung Cancer Treatment Plan and Summary

The Treatment Plan and Summary provide a brief record of major aspects of lung cancer adjuvant treatment. This is not a complete patient history or comprehensive record of intended therapies.

<table>
<thead>
<tr>
<th>Patient name:</th>
<th>Patient ID:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical oncology provider name:</td>
<td></td>
</tr>
<tr>
<td>Patient DOB: ( / / )</td>
<td>Patient phone:</td>
</tr>
<tr>
<td>Support contact name:</td>
<td>Support contact phone:</td>
</tr>
</tbody>
</table>

## BACKGROUND INFORMATION

- **Diagnosis:**
  - Lung cancer, N2, T3, Mx, Stage IIIb

- **Tobacco use:**
  - Current smoker

- **Major comorbidities:**

- **Location:**
  - LUL, LML, RUL, RML, RLL

- **Relevant preoperative findings:**
  - ECOG performance status: 2

- **Definitive surgery:**
  - Date: 5/23/2014

- **Procedure:**
  - Lobectomy

- **Notable surgical findings/comments:**

- **Completeness of resection:**
  - R0, R1, R2

- **TNM stage:**
  - T3, N2, M1

- **Pathologic stage:**
  - IIIb

- **Final pathologic details:**

### TREATMENT PLAN

**Therapy:**
- **Chemotherapy regimen:**
  - Doxorubicin 50 mg/m² q3w
  - Paclitaxel 175 mg/m² q3w

**Other:**
- **Dose reduction:**
  - Yes

**% doses administered:**
- Yes

### TREATMENT SUMMARY

**Pre-treatment weight:** 45 kg

**Post-treatment weight:** 45 kg

**Chemotherapy start date:** 5/23/2014

**Chemotherapy end date:** 8/1/2014

**ECOG performance status at start of treatment:** 2

**ECOG performance status at end of treatment:** 2

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Important Notice: This is a summary document whose purpose is to review the highlights of the lung cancer chemotherapy treatment plan for this patient. This document is not intended to replace the medical record or provide medical advice for treating lung cancer or any other disease and is not a substitute for the independent medical judgment of the treating professional.
Adjuvant Non Small Cell Lung Cancer Treatment Plan and Summary

<table>
<thead>
<tr>
<th>FOLLOW-UP AND SURVIVORSHIP CARE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Provider with primary responsibility for follow up care:</strong></td>
</tr>
<tr>
<td>Follow up care</td>
</tr>
<tr>
<td>Medical oncology visits</td>
</tr>
<tr>
<td>Imaging – Chest CT w/contrast</td>
</tr>
<tr>
<td>Non-contrast chest CT</td>
</tr>
<tr>
<td>Cancer screening (based on individual risk)</td>
</tr>
<tr>
<td>• All patients – Colonoscopy</td>
</tr>
<tr>
<td>• Women – Mammogram</td>
</tr>
<tr>
<td>• Women – Pap smear</td>
</tr>
<tr>
<td>• Men – PSA/DRE</td>
</tr>
</tbody>
</table>

Potential late effects of treatment(s):

Call your doctor if you have any of these signs and symptoms:

<table>
<thead>
<tr>
<th>Needs or concerns:</th>
<th>Referrals provided:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Smoking cessation:</td>
<td>□ Pulmonary rehabilitation</td>
</tr>
<tr>
<td>□ Prevention and wellness:</td>
<td>□ Smoking cessation counselor</td>
</tr>
<tr>
<td>□ Emotional or mental health:</td>
<td>□ Physical therapist or exercise specialist</td>
</tr>
<tr>
<td>□ Personal relationships:</td>
<td>□ Dietician</td>
</tr>
<tr>
<td>□ Fertility:</td>
<td>□ Psychiatrist</td>
</tr>
<tr>
<td>□ Financial advice or assistance:</td>
<td>□ Psychologist</td>
</tr>
<tr>
<td>□ Other:</td>
<td>□ Social worker</td>
</tr>
<tr>
<td></td>
<td>□ Other:</td>
</tr>
</tbody>
</table>
PILOTING AN INTERVENTION TO IMPROVE CONTINUITY

Project Inquiry References


http://www.ahrq.gov/cahps/about-cahps/cahps-program/cahps_brief.html


http://asco.org/ASCO/downloads

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Kentucky Department for Public Health (KDPH) and the Centers for Disease Control and Prevention (CDC). Kentucky Behavioral Risk Factor Survey Data. Frankfort, Kentucky: Cabinet for Health and Family Services, Kentucky Department for Public Health, [2012].


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