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Utilizing Telecommunication to Provide Patient Centered Care for Adults

Newly Diagnosed with GI Cancer: A Quality Improvement Project

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Date of Submission: November 8, 2019

Table of Contents

Abstract	3
Introduction.....	5
Problem Description.....	5
Available Knowledge.....	8
Rationale.....	11
Specific Aims.....	14
Methods.....	15
Interventions.....	22
Study of the Interventions.....	24
Measures.....	25
Analysis.....	28
Results.....	29
Summary.....	35
Interpretations.....	36
Limitations.....	38
Conclusions.....	39
Funding/ Acknowledgements.....	44
References.....	43
Appendices.....	50

Abstract

INTRODUCTION: A confirmed diagnosis of GI Cancer causes anxiety and stress as patients become overwhelmed with questions, worries and fears. At diagnosis, patients are not yet formally connected to the support services available to those actively receiving chemotherapy, creating a “gap period”. To help reduce anxiety, as well as, foster therapeutic relationships and improve overall patient experiences, a structured telephone communication by the gastrointestinal cancer oncology nurse practitioner (GI NP) was proposed.

AVAILABLE KNOWLEDGE: Reduction of anxiety has been shown to enhance the quality of life, increase compliance with a prescribed treatment plan and foster the ability to sign informed consent. Nurses play an important role in reducing anxiety by creating an environment in which patients are able to develop trusting relationships to communicate their concerns. A navigation program helps to reduce the gap in oncology care between diagnosis and the start of treatment and connect patient to services which can provide support, education and guidance to the newly diagnosed GI oncology patient.

METHODS: The self-reported PROMIS Anxiety Scale short form and the NCCN Distress Thermometer were used to measure anxiety and distress pre and post-intervention along with the Patient Satisfaction with Cancer Care (PSCC) satisfaction tool post-intervention to gauge patient satisfaction. A Paired t-test was utilized to evaluate the effect of the intervention on the PROMIS anxiety scores and the NCCN distress scores.

INTERVENTION: Telephone communications were made to patients by the GI NP within 48 hours of the diagnostic visit. Weekly communications were then scheduled as needed until the

patient's treatment began, as requested by the patient, or as determined necessary by any issues or concerns that arose. A final visit was made at the start of care.

RESULTS: In this quality improvement study, 16 patients were evaluated over 3 months.

Anxiety scores demonstrated a statistically significant reduction from pre to post intervention $m=4.375$, 95% CI [$SD 7.92$, $p .043$). There was no significant difference in distress scores.

Patient satisfaction responses ($n=8$) indicated very high levels of satisfaction with the telephone communications.

CONCLUSIONS: Although this QI study was small, results indicate a significant improvement in anxiety levels with telephone communications during the gap period between diagnosis and the start of care. This demonstrates an important role for navigators in increasing the outreach to patients at this time. Our feedback indicated patients felt more connected to the clinic and more trusting of their relationship with their providers at the initiation of treatment. Ideally, this project should be continued on a much larger scale for more valid results.

Keywords: Oncology, oncology nurse practitioners, nurse navigators, cancer care, anxiety, distress, telephone communication, patient satisfaction.

Utilizing Telecommunication to Provide Patient Centered Care for Adults

Newly Diagnosed with GI Cancer: A Quality Improvement Project

Introduction

Global Problem

The estimated number of new GI cancer diagnoses in 2018, including all diseases of the lower esophagus and digestive tract, was estimated at 319,160 (American Cancer Society, Cancer Facts and Figures, 2018). The number of deaths in the same year were estimated at approximately 50%, or 160,820 (p.4). Depending on the stage when diagnosed, many of these cancers are incurable, therefore treatment is focused on increasing overall survival in terms of months to a few years. When faced with the diagnosis of a terminal illness, patients experience a variety of stress related symptoms including depression and anxiety, that impact their physical, emotional and social well-being, significantly diminishing their quality of life (Institute Of Medicine, 2008).

The journey into a GI cancer diagnosis begins with a symptom or illness, generally consisting of fatigue, weight loss or other GI distress which has already led to some degree of anxiety. This is often followed by tests or exams that point to the likelihood of cancer and the patient may be referred to a tertiary cancer center for further testing for confirmation and staging of the disease, treatment planning and implementation. At the time of referral, the patient, their family and loved ones may be fearing for the worst but hoping for the best. Most often, if the patient is to begin treatment, more testing may be required in the form of endoscopic biopsies, genetic testing, or placement of specialized intravenous lines for chemotherapy.

Preparing a patient to initiate chemotherapy can take some time. In some instances, certain medical issues such as chronic kidney disease may need to be optimized, or, the patient may require placement of specialized implanted ports for chemotherapy administration. This can take a few days, or, potentially, a few weeks depending on the prescribed plan of care.

Local Problem

At this major cancer center in Boston, MA, patients can be referred from primary care offices, remote areas where oncology services are not available, community hospitals and cancer centers, or, are sometimes self-referred. A new patient nurse navigator helps establish an initial appointment with a GI oncologist in the practice, then books the patient for the next multidisciplinary diagnostic and treatment planning appointment within 1-5 days. Once the patient has this diagnostic appointment, the relationship between the new patient nurse navigator and the patient ends, as her role is only to help establish patients with an oncologist.

Patients meet their GI oncologist, radiation oncologist and surgeon at the multidisciplinary clinic. Here, all tests and diagnostic imaging is reviewed with the patient to reach a diagnosis and a treatment plan is established. If chemotherapy is indicated, schedulers will set up an appointment which is usually within a week. If an implanted port is necessary for chemotherapy, those appointments will be arranged as well.

This “gap” period, the time between the diagnostic visit and the start of care, is a time of significant anxiety for the patient and one in which the staff of the oncology clinic believe patients have no formal contact person to ask questions or seek further information. Until they are being treated in the clinic as active chemotherapy patients, appointments to meet with nurses for education, social service practitioners, the psych-oncology specialists, nutritionists, or, the

massage or acupuncture therapists for symptom relief are not scheduled, leaving a gap in patient support.

Another stressor is that when a patient presents for chemotherapy on their scheduled treatment day, it is often expected that they will sign informed consent. At times, their anxiety can be so high, or they have so many unanswered questions, consent cannot be obtained. This can lead to a delay in the start of treatment as the patient and family take more time to process information and make decisions about their care. In some cases, the postponement of treatment is time certain patients cannot afford in terms of the aggressive nature of their disease.

Inadequate communication between clinician and patient during this time delays the development of a therapeutic relationship necessary to build trust. This can lead to a great deal of emotional distress (National Academies of Sciences, Engineering, and Medicine, 2018). This emphasizes an important role for patient navigators who can help build relationships between patients and the medical system facilitating the relief of fear and anxiety (p.10). The GI oncology nurse practitioners (NP) possess advanced knowledge of the specific cancer diagnosis, treatment regimens and expected outcomes, as well as, a holistic nursing education prepared to assess and address psychosocial and educational needs. They are in a unique position to act as navigators to the patients who have received a GI cancer diagnosis and are awaiting the start of treatment.

It is proposed that a telephone communication from a GI NP to a patient who has received a GI cancer diagnosis and not yet started treatment would serve as a bridge to connect the patient to the oncology clinic. The purpose of the telecommunication would serve the following purposes:

1. Provide education - The telephone communication can be used to answer questions regarding tests, or, to clarify information about symptoms. In addition, teaching could

begin regarding the upcoming chemotherapy regimen which would allow more time for processing information prior to the start of treatment. This could aid in reducing anxiety and improve knowledge for informed consent.

2. Alleviate anxiety - The telephone communication can help address any emotional concerns and the role that any stress or anxiety may be playing in their ability to learn or adhere to the prescribed treatment plan. Information gathered in this assessment can be used to refer patients to the appropriate resources sooner.
3. Allow for open communication - The telephone communication will seek to engage the patient in an open-ended conversation to address any other concerns they may have. This may include worries regarding work related issues, finances, or how to inform young children about their diagnoses. Information about any services and contact information if available can be provided at this time.

Available Knowledge

Advances in cancer diagnostics and treatment have made the care of oncology patients increasingly complex. Historically, treating a patient with cancer was as simple as having a treatment option or transitioning them to hospice care (“The State of Cancer Care in America, 2016,” 2016). Now, state of the art medical care, advanced diagnostic equipment, and the development of molecular tumor testing with targeted chemotherapy, has allowed patients to receive unprecedented cancer care. The multidisciplinary team (MDT) approach in oncology care is increasingly important in managing patients and has resulted in improved coordination of care and higher patient satisfaction with services (Abdulrahman, 2011). It is because of the MDT

approach, that patients can transition from diagnosis to treatment in a far shorter period of time than years ago leading to increased survival.

The challenge, however, is how to improve care after the MDT and before the patient is fully engaged in the GI oncology clinic. This “gap period”, the interim time between the MDT and the start of treatment can be a great source of stress (National Academies of Sciences, 2018, p. 10). Anxiety associated with the diagnosis of cancer is well established in the literature as a significant factor impacting the quality of life of oncology patients. During this gap period and together with concerns about physical symptoms of pain, nausea or fatigue, patients experience emotional distress associated with worries about changes in body image and inability to fulfill their roles within their relationships with loved ones or within the family structure.

Dutch researchers demonstrated that patients presenting to MDT for diagnosis of colon cancer experienced high levels of anxiety both prior to, and after MDT by using the short Dutch version of the Spielberger State -Trait Anxiety Inventory (STAI-6) to measure anxiety levels (Bronner, Nguyen, Smets, van de Ven, & van Weert, 2018). Using this tool, a cutoff point for diagnosing high levels of anxiety was identified as a score of 44. In a final sample size of 81 patients (10 patients were excluded due to incomplete data), average anxiety score before GI diagnostic consultation, which researchers labeled T1, was 46.30 ($SD = 11.29$). There was a statistically significant decrease in anxiety scores from T1 to T2, $t = 3.149$, $p = .002$. The mean decrease was 4.61, 95% CI [1.70, 7.52], $d = 0.40$, indicating a small to moderate effect size. However, after GI diagnostic consultation, 37% of patients ($n = 30$) still experienced clinically high levels of anxiety (Bronner et.al., 2018). Although this study does demonstrate a small to moderate decrease in anxiety levels from pre to post GI diagnostic consultation, there are patients still experiencing high levels of anxiety after diagnosis, indicating a need for continued

support throughout this timeframe as they transition into treatment. The “Measuring Your Health Study”, published in 2016, recruited 2968 oncology patients between 2010 and 2012 and evaluated the responses on eight Patient Reported Outcome Measurement Information Systems (PROMIS) tools (Jensen et al., 2016). Patients were recruited from four population-based cancer registries, 6-13 months after they were diagnosed with primary colorectal cancer, lung cancer, non-Hodgkin lymphoma, breast cancer, gynecological cancer or prostate cancer. An initial survey was administered and then a follow up survey was sent in six months. The survey included PROMIS measures evaluating physical function, fatigue, pain interference, anxiety, depression, ability to participate in social roles, cognitive function and sleep disturbance. PROMIS uses a T-score metric of 50 as a mean reference range for normal levels of anxiety for the U.S. population (PROMIS, 2019). For the T-score anxiety measure, the baseline mean score for patients 6 months after diagnosis was 48.5 ($n=2946$, $SD=10.1$) with the follow up score 6 months later of 48.7 ($SD=11.2$, $p=.21$) (Jensen, et al, 2016). Although this study has limitations in that patients coping skills play a role in their levels of anxiety and there was variability in the timing of the initial survey of 6-13 months after diagnosis, it does demonstrate that even several months later, patients demonstrate stable levels of anxiety that borderline on the clinically significant level of 50. These two studies are important in that they demonstrate that anxiety is a factor for oncology patients throughout the trajectory of care and should be a focus for physicians, nurse practitioners and all members of the healthcare team from the diagnosis phase until end of life.

Nurse navigators play a key role in patient triage, coordination of diagnostic tests, and assessment of the informational and psychosocial needs of the patients (Hebert & Fillion, 2011); thus, can be a critical resource in the interim period while patients are waiting for a return

appointment to initiate treatment. The National Cancer Institute (NCI) describes patient navigation as “the support and guidance provided to persons with abnormal screenings or new cancer diagnosis, including overcoming challenges and barriers to accessing the health care system in a culturally competent manner” (Freund et al., 2008). Navigation programs help to reduce gaps in care by improving the access to cancer care and the timeliness of the services throughout the cancer care continuum. The first phase of this continuum begins when there is an abnormal finding and the patient receives a diagnosis of cancer. In this stage, it is important that the individual needs of the patient and family are addressed, and the oncology nurse navigator can help coordinate psychosocial and educational support (Riley & Riley, 2016).

There are a number of resources available to patients for help with managing anxiety such as social service, palliative care and the psych-oncology service but unfortunately, these are available after the patient initiates treatment. To address knowledge deficits regarding treatments and expected side effects, educational resources are available to patients ready to begin treatment. These include videos, live educational offerings and reading material often provided to patients as they begin treatment. This project seeks to fulfill a need for those patients who have received a diagnosis but are still waiting for treatment to begin and do not have access to the same services that active treatment patients can receive.

Rationale

A multidisciplinary team conference in which a patient receives a diagnosis of cancer can be very stressful. Patients receive a lot of information at diagnostic conferences which can make it challenging to understand and retain everything that is said. Once the patient returns home and begins to process all the information, often more questions are generated which can lead to increased anxiety. Hildegard’s Theory of Interpersonal Relations focuses on the therapeutic

process of the nurse-patient relationship and can provide a framework for the navigator role in reducing anxiety and distress with the newly diagnosed GI oncology patient (Peplau, 1997).

Nurses play an important role in creating an environment in which patients are able to develop trusting relationships where they are comfortable communicating for support and knowledge. Effective communication is essential in these interactions and without it, the development of a therapeutic relationship between provider and patient cannot occur (Peplau, 1997). Within Peplau's theory is the core concept that effective communication is an integral part of the nurse-patient relationship, and without it, there is a large risk that any efforts at education may be unsuccessful. The application of this theory can guide the oncology NP to use the intervention of telephone communications to provide support, education and guidance to the newly diagnosed GI oncology patient. This fosters the goal of decreasing anxiety through enhanced knowledge and support during a phase of oncology care when a patient is not otherwise connected to formal support services. Within this framework, four phases of the nurse-patient relationship are identified, orientation, identification, exploitation and resolution, the first three of which drive the goals of the GI NP intervention.

As the telephone communications begin between the GI NP and the patient, the orientation phase and the identification phase happen almost simultaneously. The orientation phase begins with the first telephone communication as the patient is oriented to the NP navigator role as the primary source of educational, social and emotional support until formal treatment begins and other resources can be accessed. The telephone communication becomes an avenue for patients to ask questions and seek further information regarding their diagnosis, helping to relieve any anxieties they have with unanswered questions. It is with this that the oncology journey begins as the GI NP, acting in a nurse navigator role, identifies the needs of the

patient and helps to establish a plan of care. If the patient's start of treatment is prolonged excessively due to medical cause, it is possible that the exploitation phase may begin earlier. In this circumstance, resources such as physician specialists, nutritionists, or social workers, could be involved sooner to help optimize the patient for cancer treatment. The ending of a therapeutic relationship between a nurse and a patient in Peplau's theory, is termed the resolution phase, and signifies the point where the established goals of the encounter have been met (Sheldon & Faust, 2014, p. 70). In outpatient oncology care, the relationship between the nurse / nurse practitioner and the patient is often a long term one that may end with the death of a patient and therefore is not entered as part of this project.

In 2014, an Iranian randomized clinical trial ($n=74$) examined the pre and post anxiety scores measured by the Hospital Anxiety and Depression Scale (HADS) for coronary artery bypass surgery candidates (Zarea, Maghsoudi, Dashtbozorgi, Hghighizadeh, & Javadi, 2014). The intervention was the use of a therapeutic Peplau communication model which consisted of seven communication sessions in the four stages of Peplau's theory. The results demonstrated that pre-therapeutic communications, the intervention group had a mean anxiety score of $m=10.73$ and the control group $m=10.26$. Post-treatment scores showed the intervention group as having decreased scores ($m=9.38$) and an increased score in the control group ($m=11.62$).

A study done at the University of Vermont Health Network in 2018, examined the influence of the breast cancer nurse navigator role in reducing distress utilizing the concepts of Hildegard Peplau's Theory of Interpersonal Relations (Johnson, 2018). Paired samples testing was used to analyze the pre and post- intervention scores of 18 newly diagnosed breast cancer in this descriptive quantitative study in which patients met with a breast cancer navigator in a single educational session to discuss upcoming surgery, available resources and emotional support.

The study demonstrated a statistically significant difference in scores between pre-intervention distress ($M = 7.44$, $SD = 2.68$) and post-intervention distress ($M = 2.94$; $SD = 1.86$). A paired sample test confirmed a significant correlation between the intervention and reduction in distress from pre-intervention to post-intervention ($C = .535$; $p = .022$). The author reported the study's threat to generalizability and limitations as a small sample size, only conducted at a single institution and a homogenous sample of white females. However, despite this, the results are important as they demonstrate a clinically important reduction in distress for those patients who had intervention from the breast oncology nurse navigator indicating that the use of therapeutic communications that incorporate Peplau's framework can have a positive impact.

Specific Aims

The purpose of this quality improvement project is to collaborate with and empower patients with the knowledge and resources necessary to bridge the gap in care between the time of diagnosis and the start of gastrointestinal cancer treatment.

Aims: The implementation of a program which incorporates telephone communication to patients during the period of time from diagnosis of GI cancer to the start of chemotherapy care will:

- Reduce anxiety as measured by PROMIS Anxiety Scale – short form
- Reduce patient identified distress as measured by the NCCN Distress Thermometer
- Enhance patient satisfaction measured by the Patient Satisfaction with Cancer Care quality measure at the end of the QI project time

- Prevent start of treatment delay due to increased anxiety, distress or lack of knowledge which prevents the ability to make an informed decision of consent.

Methods:

Context

This quality improvement project was performed in an outpatient GI Oncology clinic at an urban, Boston hospital, that is considered one of the largest cancer centers in New England. A GI cancer diagnosis includes any disease of the upper and lower digestive tract, liver, biliary tree, pancreas and appendix and patients are generally referred from a primary care provider or other specialist, and in some cases, seeking second opinion. A nurse navigator assists patients to an appointment with the multidisciplinary GI team within a week of request, and sometimes within just a few days. The patient meets with the multidisciplinary GI oncology team for confirmation of diagnosis and development of a treatment plan. At times, further testing may be required to confirm diagnosis and the patient would be assisted to schedule these appointments. If diagnosis is already established, the patient is provided treatment recommendations and is given an appointment for a treatment start date in the GI clinic. This appointment is typically the following week and includes signing consent, receiving education about side effects and starting chemotherapy all in the same visit. This can be quite overwhelming for patients who present already anxious about just having learned they have cancer and are now expected to provide consent without opportunity to really think about what options they may have.

The clinic is staffed daily by 2-3 physicians and 3-4 nurse practitioners who see an average of 80-100 patient visits per day. There are also three registered nurses who assist with blood draws, patient teaching and triage, as well as, several medical assistants and patient

schedulers. The clinic has many supportive resources for patients including social service, palliative care, nutrition, and psych-oncology. All chemotherapy is administered in a separate infusion unit located within the cancer center.

Patients for this project will be recruited from the new patient pool during a new patient visit. Included will be patients with diagnosis of any GI cancer who will be remaining a patient at the cancer center for continued treatment and follow up. It will not include patients who have come to MDT for confirmation of diagnosis with recommendations but will be receiving their care closer to their homes.

Cost Benefit Analysis

The stakeholders for this project include the GI oncologists who wish to have their patients initiate treatment as early as possible, the GI NP invested in providing the resources necessary to develop patient connectedness, the clinic RN's who value the holistic needs of the patient and the remainder of the oncology team who care for these patients throughout the trajectory of care. The most important stakeholder in this project is the newly diagnosed GI cancer patient, who fears the worst, yet is hoping for the best, is full of anxiety and worry about what the future holds and needs support and education to maximize their quality of life.

The first step in determining the cost/benefit ratio of this quality improvement project, is to analyze the initial treatment visit planned for the patient. This appointment is booked as a 30-minute visit and the context of the appointment consists of the following:

1. General Discussion including, but not limited to, an introduction to the clinic procedures and policies, explanation of treatment schedule and appointments and an overview of available resources

2. Examination - including interval history, evaluation of new problems since diagnosis, comprehensive physical examination and evaluation of laboratory data, radiology reports, vital signs (inclusive of height and weight for chemotherapy ordering)
3. Informed consent - This is an extensive review of a discussion that occurred in the multidisciplinary clinic and includes the alternative to treatment and an explanation of why the regimen was chosen. This discussion also includes education regarding chemotherapy agents and their specific side effects, as well as, information on how to manage these effectively and prevent further complications.
4. Opportunity for questions and open-ended discussion

This visit is billed as a Level 5 (the highest billing code available for an outpatient visit). A level 5 visit must meet 2 of the following criteria:

1. Comprehensive history
2. Comprehensive exam
3. High complexity medical decision making

(E.M. University, 2019)

According to the charge file for this facility (2018), the billing charge for a level 5 visit is \$748.

If the patient arrives to this visit anxious, overwhelmed, and unable to comprehend all the information presented, informed decision making is not possible. At this point, the start of chemotherapy is cancelled for that day and rescheduled for a later visit, often another week away. This delay in treatment can have serious implications on the quality of life and life

expectancy of the patient. From a financial perspective, another visit is billed to the insurance company and the patient may be responsible for an additional co-pay.

The subsequent financial implications of a cancelled chemotherapy treatment session are complex. If the treatment regimen was special ordered and delivered from an outside source in preparation for that day, then the financial loss can be enormous if storage is not available. In addition to this, the infusion unit is staffed with registered nurses based on the number of chemotherapy patients booked for the day. Finally, due to high volume of patients booking chemotherapy treatment, it is often difficult to find open appointment times in the infusion room for patients. This limits patient choice with regards to morning or afternoon timing and decreases patient satisfaction with scheduling. Considering the vast majority of patients who are receiving active chemotherapy treatment are middle age men and women who are still working and raising families, choices with scheduling plays a large role in their satisfaction with care. Due to the financial constraints, cancer and the subsequent treatment places on their lives, many continue to try to work for as long as possible and prefer to arrange their chemotherapy sessions around their work schedule. Efforts should be made to reduce unnecessary cancellations for this reason as the rescheduling process places burden on future schedules.

It is estimated that 6 patients per week will be eligible from the GI multidisciplinary clinics to participate in this quality improvement project. These patients will require a phone call within 48 hours and most will require a follow up phone call the following week. A phone call will be placed weekly until the patient has their initial treatment visit. Almost 100% of patients have a follow up appointment with treatment scheduled within 7-10 days. Based on 1 patient cancellation per week although this number can be higher and fluctuates weekly.

Table 1 Tangible Costs of the Project		
Item	Charge	Total Cost
Project Leader	\$60/hr x 6pts/wk x 3hrs/pt	\$4320
Mentorship by MD colleague	Estimated salary x 1-2 hrs/wk	\$10,000
Time spent by oncology team	Estimated salary x 30min/wk	\$600
Paper and supplies		\$500
Estimated Total cost of project: \$15, 420		

Table 2		
Tangible savings from the project		
Item	Charge	Total Saved
Institutional Savings		
RN salary savings	\$60/hr x 12 hr shift x 52 wks	\$37, 440 / year in salary savings
Savings from lost revenue	Level 5 visit \$748 x 52 wks	\$38,896 / year in benefit
NP salary saving	\$85/hr x 1 hour x 52 weeks	\$4,420 / year in salary savings
Insurance company Savings		
Savings for 2nd visit	Level 5 visit \$748 x 52 wks	\$38,896/year savings no reschedule
Patient Savings		
Parking savings	\$15 per visit	\$15 savings for extra visit
Savings commuting costs	\$25 -\$250 for travel	\$25-\$250 savings for extra visit
Savings missed work	up to \$800 / day	Savings of up to \$800 per day
Savings cost of childcare	\$100 per day for some patients	Savings up to \$100 per day
Institutional Savings for avoiding 1 patient reschedule: \$80,756/year Insurance Savings for avoiding 1 patient reschedule: \$38,896/year Patient Savings for avoiding a reschedule of appt: Up to \$1000/visit		

Explanation of Costs

1. Project Leader - \$4320 Hourly wage \$60/hour with 6 patients per week, estimated hours per patients for phone calls and documentation.
2. Mentorship of Physician Colleague - \$10,000
3. Dedication and time of oncology physician colleagues who will provide appropriate patient lists - Based on 2 hours of time with estimated wage \$600

4. Paper and supplies - \$500

Explanation of Benefits

Financial benefits:

- Institutional
 - RN salary estimated at \$60/hr x 12 hours = \$720 per day of occurrence = savings of \$37,440/year with 1 patient per week estimate
 - NP salary estimated at \$85/hr x 1 hour = \$85 per occurrence = savings of \$4,420/year with 1 patient per week estimate
 - Increased patient volume = \$748 level 5 billing charge for each additional patient that can be booked when a current patient is not cancelled = \$38,896/year savings on lost patients that could not be booked into slots taken by rebooked patients
 - \$748 level 5 visit savings if patient does not need to return for additional visit \$38,896/year in savings to insurance companies if 1 patient per week is saved from a re-book.
- Patient benefits:
 - No need for additional visit co-pay which can range from \$10 - \$100.00 depending on insurance benefit.
 - No need for additional cost of parking, commuting, lost days from work, child care costs for extra visit. Savings can range from \$10 - \$>1000.00 if missed work for additional visit.

Non-financial:

- Improved adherence to treatment (overlaps with financial due to reduced hospitalization) resulting from earlier education regarding symptom management. This can lead to improved quality of life for patients with better pain control, reduced nausea and vomiting, overall improved GI symptoms, less days missed from work and enjoying family or loved ones.
- Improved patient satisfaction with care from earlier connectedness with clinicians who can answer questions, provide necessary information and link the patient to resources as needed. This also overlaps with financial gain as improved patient satisfaction means patients continue to receive care at the hospital as opposed to seeking care elsewhere. Positive patient satisfaction data which is public information provides a magnet for attracting other patients to seek care at this facility.
- Improved self-efficacy as patients are more informed and better prepared to make decisions about their treatment options.
- Reduced anxiety and/or stress while waiting for the start of treatment – this may equate to a cost savings to the patient and or insurance company in terms of medication or in counseling, but the exact figures cannot be calculated.

Intervention

A multidisciplinary team (MDT) conference for each of the GI cancers occurs in different locations on various days of the week. For this reason, this healthcare improvement project will incorporate the new patient population of the GI Oncologist linked with the primary NP project leader.

New patients will be identified as appropriate if they meet the following criteria:

1. Have a new diagnosis of GI Cancer.
2. Will not be treated on a clinical trial (these patients have immediate access to services).
3. Will be receiving chemotherapy at the GI Oncology clinic in Boston.

Project Team:

1. Laurie Miller, MS, APRN, CNRN, GI Oncology Nurse Practitioner and Project Leader.
2. Dr. Ryan Nipp, MD, MPH, GI Medical Oncologist and Project Mentor.
3. GI Oncology MD team members who can assist in identifying appropriate new patients.

Telephone communications will take place as follows:

1. The initial phone call will take place within 48 hours after MDT for all patients who are not returning within that time frame,
2. During the initial call, the PROMIS Anxiety Scale short form will be completed, the Distress Thermometer will be reviewed, and the patient will self-identify positive findings on the NCCN Problem List.
3. For those patients who have a visit scheduled within a week, they will have the opportunity to schedule a second telecommunication visit prior to their appointment in clinic.
4. For patients who have their initial visit scheduled beyond that, they will receive weekly telecommunication visits to keep them connected to the clinic and their providers until they are seen.
5. Patients will be seen at the start of care visit and follow up surveys will be administered.

6. Patient satisfaction surveys will be bulk mailed at the end of the project. Each will include a self-addressed stamped envelope to encourage return.

Intervention protocol:

1. Introduction and purpose of call.
2. Answer any questions and address any lingering concerns from MDT.
3. Discuss chemo, appointments, provide clinic information.
4. Administer PROMIS Anxiety Scale short form.
5. Help patient identify level of distress on Distress Thermometer.
6. Discussion of concerns on NCCN Problem List.
7. Answer any new questions.
8. Arrange next telephone call if treatment does not start within 7 days.
9. Patient will be seen at the start of treatment for a visit and administration of the PROMIS anxiety short form follow up survey.

The goal of the telephone communication is to establish and maintain patient-clinician connectedness with a member of the advanced practice nursing team and provide an opportunity for the patient to ask questions, clarify information or seek further support. It is proposed that this will reduce anxiety, increase adherence to treatment plans and improve patient satisfaction with care.

Study of the Interventions

The study of the intervention occurred in 2 phases. The first phase determined the effect of the interventions on anxiety and distress. The first screening tool utilized to do this was the PROMIS scale that measured anxiety at the time of the diagnostic visit and the time of start of

chemotherapy care (Appendix A). The goal of the intervention (phone calls) was to increase connectedness, provide communication, enhance knowledge and foster access to resources not otherwise available. The intervention was structured to reduce anxiety during this "gap" period between GI cancer diagnosis and the start of treatment. In addition, a patient focused problem list that incorporates areas of physical, emotional, social and financial aspects of the patient's life, was used to identify symptoms or areas of concern to serve as a guide for subsequent phone calls.

The NCCN distress thermometer is a subjective scale that is utilized to measure the impact of symptoms on a patient and was measured pre and post intervention (Appendix B). Finally, patient satisfaction was measured using an adaptation of the Patient Satisfaction with Cancer Care (PSCC). This is a 2-part survey that focuses on satisfaction with the care provided by the oncologist during the diagnostic process and the satisfaction with the phone call interventions. The satisfaction survey was adapted by removing questions from the original version that did not apply directly to the phase of care between diagnosis and the start of treatment (Appendix C).

Measures

Anxiety in newly diagnosed cancer patients can be a normal psychosocial reaction to the stress of facing a terminal illness (Esser et al., 2018). Patients were assessed utilizing a short 8 question form which aimed to evaluate the presence of anxiety, as well as measure levels of distress. In addition, an oncology focused patient needs assessment was performed to help guide a more structured phone communication to address specific concerns.

To measure the impact the telecommunication intervention has on the level of anxiety, the short form questionnaire for anxiety developed by PROMIS (Patient Reported Outcome Measurement Information Systems) was utilized at the initial phone call and again at the start of treatment (Promis, 2019). PROMIS Cancer measures were developed under a grant from the National Cancer Institute and through the work of expert consensus and informed by focus groups and cognitive interviews with cancer patients (PROMIS-Anxiety, 2019, p.3). This tool utilizes specific questions to evaluate symptoms over the past seven days and evaluates self-reported fear, worry, tension, and misery. The PROMIS Anxiety Scale converts a patient's raw score to a T-score which is based on a mean of 50 with a standard deviation of 10 (PROMIS-Anxiety, p.4, 2019). An important concept of the PROMIS T-score is to understand that a higher score is measuring more of the concept. Thus, a patient with a higher T-score measured on the anxiety form, has a higher degree of symptoms.

Figure 1 T-Score Characterizations				
	NORMAL	MILD ANXIETY	MODERATE ANXIETY	SEVERE ANXIETY
T-Score	50 or less	50 - 60	60 - 70	> 70

Chart

Figure 1. T-Score Characterizations. This figure demonstrates how T-scores correlate with anxiety characterizations.

There exists a myriad of studies which seek to establish reliability and validity of PROMIS screening tools in a variety of diseases and conditions. In an overview article published in the *Journal of Clinical Epidemiology*, authors reviewed a series of studies to evaluate the clinical validity of the PROMIS tools in six clinical populations (Cook, Jensen,

Schalet, Beaumont, Amtmann, et.al, 2016). In their evaluation of a series of articles, they summarize clinical validity findings for nine PROMIS measures within five PROMIS domains across six clinical conditions. The authors conclude that the results support the continued application of the PROMIS tools and add to the growing body of literature that continue to demonstrate the validity and reliability of the PROMIS assessments (2016).

Anxiety in newly diagnosed cancer patients can be a normal psychosocial reaction to the stress of facing a terminal illness (Esser et al., 2018). The PROMIS Anxiety item banks assess self-reported fear (fearfulness, panic), anxious misery (worry, dread), hyperarousal (tension, nervousness, restlessness), and somatic symptoms related to arousal (racing heart, dizziness). Anxiety is best differentiated by symptoms that reflect autonomic arousal and experience of threat. Only one behavioral avoidance item is included in the adult item bank; therefore, behavioral fear avoidance is not fully evaluated. The anxiety measures are universal rather than disease-specific. All assess anxiety over the past seven days.

Beyond anxiety, patients may be experiencing distress, or unpleasant feelings that include fear, hopelessness, sadness, guilt, uncertainty or powerlessness (American Cancer Society, n.d.). A tool utilized to measure a patient's level of distress is the National Cancer Care Network (NCCN) Distress Thermometer and Screening Problem List (Cuttillo, et al., 2017). This screening tool focuses on areas that include distress which may occur in practical situations such as work, home or child care, family concerns regarding health issues or worries about sterility, emotional concerns regarding fear or sadness, and numerous physical complaints such as pain, weight loss and concerns about appearance. The positive answers on this screening tool were used to help guide subsequent telecommunications with the patient and identify areas that may require referral to specialties.

Evaluation of patient satisfaction with cancer care is an important quality measure for improving care delivery in health systems and was done for this project. The Patient Satisfaction with Cancer-Related Care PSCC is a quality measure developed to evaluate satisfaction with the broad scope of cancer care from screening to diagnosis and treatment, rather than focusing on specific aspects of cancer related care (Jean-Pierre et al., 2010). This tool has been adapted to focus on the specific interim of care that begins with diagnosis at multidisciplinary clinic and ends with the start of treatment and identify patient satisfaction with that process and more specifically how the telephone communication impacted that process

Analysis

Quantitative data gathered on the PROMIS anxiety short form and the NCCN Distress Thermometer was organized in an Excel chart and exported and analyzed with JMP and SAS software. Pre and Post intervention scores were evaluated using a paired sample t-test and compared for changes. Further comparison was performed by identifying any differences in male vs female responses. A frequency table demonstrates scores from the PROMIS form and Distress scores, before and after the interventions were completed to show effect. Descriptive characteristics of the population were analyzed for age, sex, type of GI cancer and the number of interventions.

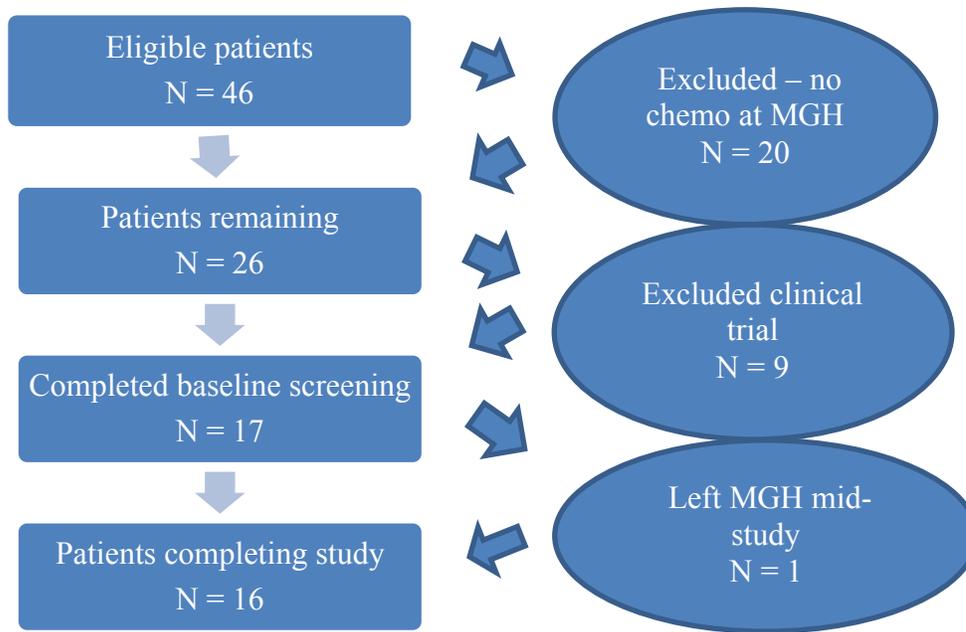
Patient satisfaction surveys were designed to provide quantitative and qualitative data. The numerical data was analyzed statistically for trends and patterns to determine the impact of the telephone communications on patient's satisfaction with this phase of their cancer care. Open ended questions provided qualitative data and were an opportunity for patients to express their experiences and perceptions in their own words.

Ethical Considerations/Protection of Human Subjects

This project was reviewed through the processes identified by the Office of Quality and Safety and met all criteria for quality improvement work and thus did not require approval through the IRB. All documentation of patient information and survey results were kept in a password protected file known only by the primary investigator to prevent access by unauthorized users. Once the information was transcribed into a data analysis chart, everything except numerical data was deleted. There were no ethical concerns and patients were at no risk of harm by receiving the telephone intervention. All patient satisfaction surveys were mailed to participants and the completion of the project to prevent possible breach of confidentiality. Privacy was further ensured by mailing satisfaction surveys to patients and providing a return envelope that was pre-addressed and stamped to enhance the return rate.

Results

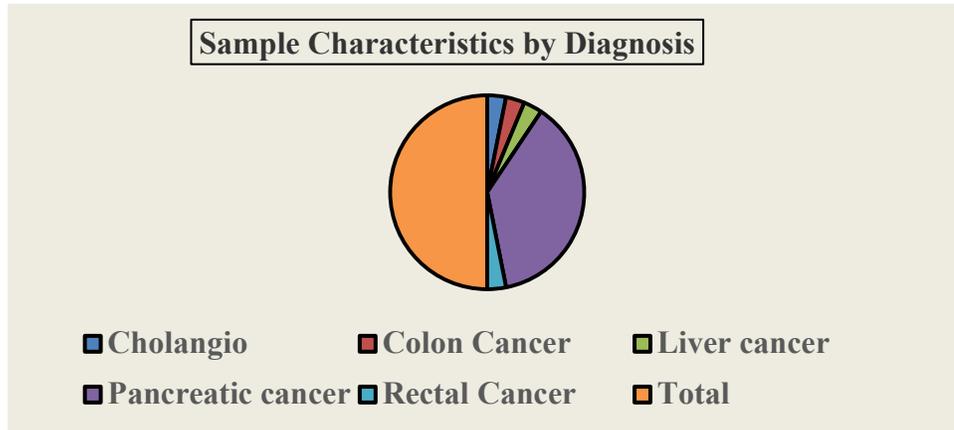
The initial patient accrual for this quality improvement project began on June 10, 2019 and finished on September 16, 2019. During that time frame 46 new patients were seen to establish a diagnosis of GI Cancer.



Flow Diagram

Figure 2. Patient accrual flowchart. This figure demonstrates the process by which the sample size was achieved.

The project included 16 patients, consisting of 9 males and 7 females. A number of newly diagnosed GI cancer patients were excluded from this QI project because they were either seeking second opinion or confirmation of diagnosis and not planning on receiving treatment at the cancer center in Boston. Of the 16 patients, 12 of them were diagnosed with primary pancreatic cancer and the others consisted of liver (1), cholangiocarcinoma (1), rectal (1), and colon (1).



Pie Graph

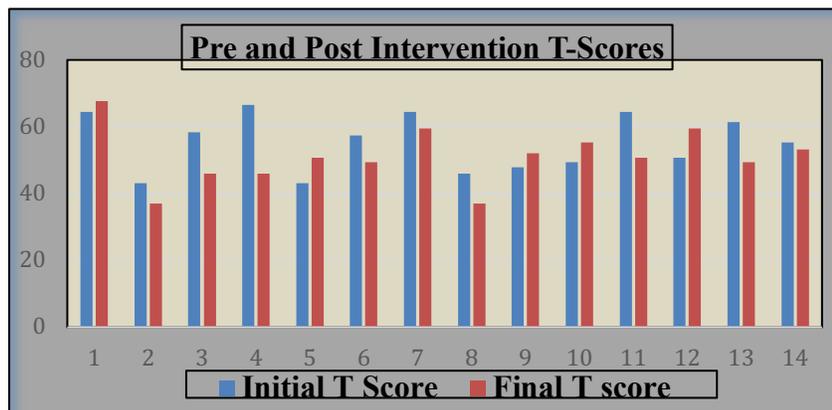
Figure 3. Participant Characteristics by Diagnosis. This figure illustrates the composition of the patient participants.

Their ages ranged from 36 years to 84 years with a mean age of 67 years old. The number of days from diagnostic visit to start of care ranged from 5 - 31 days with a mean of 12 days. The number of telephone communications patients received ranged from 1 - 4 calls, with 7 patients receiving 1 telephone call and 6 patients receiving 2 calls.

The initial screening tools were planned to be disseminated at the diagnostic evaluation but scheduling conflicts prevented the GI NP from being present at all new patient visits and therefore some PROMIS screening questions and distress thermometers were completed by email and others were completed with the initial phone call intervention. Since some patients were hospitalized for unstable medical conditions during the time between the initial GI Cancer diagnosis and the start of chemotherapy date, some telephone communications did not occur on the scheduled dates as had been planned. However, all patients were reached within 48 hours of their discharge from the hospital to resume participation in the project.

A PROMIS score below 50 is considered a normal level of anxiety on the established PROMIS measurement scale. Using a paired t-test analysis the data demonstrated a statistically

significant improvement in anxiety scores $m=4.375$, CI 95% [SD 7.92, p .043]. Pre- intervention only six patients (37.5%) scores met the established criteria as compared to post-intervention anxiety scores in the normal range (<50) at 75% ($n=12$). In addition, pre-intervention scores of five patients (31.3%) met criteria for mild anxiety (score 50-60), four patients (25%) met criteria for moderate anxiety (score 60-70) and one patient (6.3%) met criteria for severe anxiety (score >70). Post-intervention scores demonstrated significant improvement with 75% of patients ($n=12$) with scores in the normal range. There were no patients characterized as having severe anxiety, and only one (6.3%) patient with mild anxiety. There continued to be three patients with moderate anxiety (18.8%) but overall, the numbers of patients with scores higher than 50 post-intervention was only four compared with ten pre-intervention.



Graph

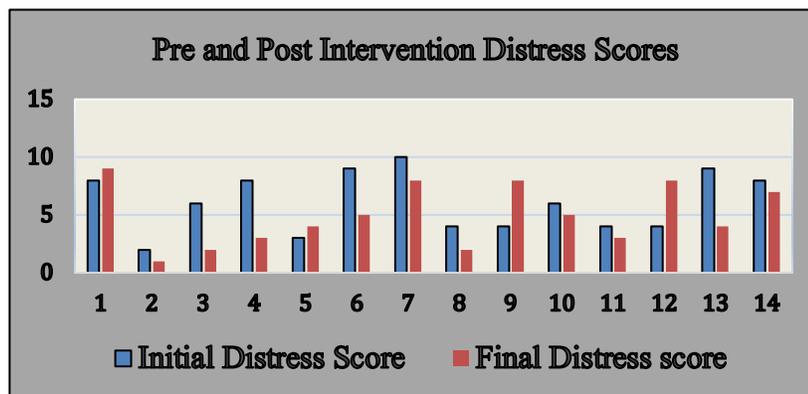
Figure 4. Pre and Post Anxiety Scores. This figure is a visual graphic of the improvement in anxiety from pre to post-intervention

Patient self-rated distress using the NCCN (National Comprehensive Cancer Network) Distress Thermometer (Cotillo et al., 2017) at the initial phone call (pre- intervention) and again post-intervention at the start of care.

The distress thermometer ranks distress on a scale of 1 (least amount) to 10 (maximum amount) and does not provide any qualification for that distress except to ask the patient to

consider the previous seven days. Distress scores did not demonstrate a statistically significant change pre and post intervention ($p = .471$) (Figure 6), however, the results are clinically meaningful because scores did decrease in 14 out of 16 patients. It is important to note that of the two patients who did not have improvement in their distress scores did have a complicated course of events between diagnosis and the start of treatment. One patient required a lengthy hospitalization for medical complications and required procedural interventions for stabilization. The other patients unfortunately learned that her cancer diagnosis which was originally thought to be curative turned out to be metastatic, changing her treatment plan to palliative.

Distress on the NCCN thermometer is broadly defined as emotional, physical, psychological, social, financial or spiritual concern and is more difficult to not only effectively characterize but also difficult to significantly impact in such a short period of time. This may explain why there is not a statistically significant impact on all distress scores with the phone call interventions but certainly an important downward trend.



Graph

Figure 5. Pre and Post Intervention Distress Scores. This figure demonstrates the change in pre and post intervention distress scores.

The positive responses identified on the patient problem list associated with the distress thermometer were used only as a guide for phone call communications and potential identification for referral needs, therefore, no statistical analysis was performed on that information.

The PROMIS scores and patient reported distress scores from the time of GI Cancer diagnosis (before the phone call interventions) and at the start of chemotherapy visit (after phone call interventions) were also analyzed using a paired t-test in SAS. This analysis demonstrates a mean decrease of .625 95% CI [*SD* 3.38, *p* .471].

Patient satisfaction data was also analyzed and evaluated for program success at the completion of the intervention. Only eight patient satisfaction surveys were returned (50% return rate). Most responses were positive indicating an overall satisfaction with the telephone communications. Negative responses were recorded in 2 areas. The first was on the question “I felt I had enough time with my doctor” of which 25% or n=2 responded “no”. The second question in which patients responded negatively was one which asked if making a follow up appointment was easy and one respondent replied “no”.

Satisfaction surveys also provided some qualitative data as patients were able to write comments with feedback. The three comments which related specifically to the telephone communications included “It was great to have someone that I could relay my questions to as it was difficult getting through to the doctor”. Another person wrote “the phone calls were very informative and the nurse practitioner really took the time to answer all of my questions. I didn’t feel as anxious about starting my chemotherapy the following week”. Finally, the third comment stated “the phone calls were really helpful especially after I got out of the hospital. I was really anxious then and just knowing that everything would still be on track with my chemo calmed my

nerves. It also helped to know that my doctors in the outpatient clinic knew what had happened while I was in the hospital”.

Discussion

Summary

This QI project had 4 specific aims:

- Reduce anxiety as measured by the PROMIS anxiety short form.
- Reduce patient identified distress as measured by the NCCN distress thermometer.
- Enhance patient satisfaction measured by patient satisfaction scores at the end of the QI project time.
- Prevent start of treatment delay due to increased anxiety, distress or lack of knowledge which prevents the ability to make an informed decision of consent.

The first aim, reducing anxiety as measured by the PROMIS Anxiety Scale was achieved by implementing telephone communications to newly diagnosed GI cancer patients within 48 hours of diagnosis and recurring weekly until they started chemotherapy. The purpose of the telephone communications was to introduce the patient to the role of the GI NP in their continuation of their care, provide information about the clinic operations, educate with regard to symptom management and address any needs identified on the NCCN patient problem list.

The second aim, reducing patient identified distress as measured by the NCCN Distress Thermometer, was not achieved. Distress is broadly defined as emotional, physical, psychological, social, financial or spiritual concerns that the patient may be experiencing and can

change categories frequently. This can make it difficult to have a significant impact on distress in such a short period of time.

Patient satisfaction with this phase of cancer care was the third aim of this QI project and was measured with an adapted version of the Patient Satisfaction with Cancer Care survey tool. Adaptations made included removing questions that did not apply to this specific phase of cancer care and those in which the patient would not yet be able to objectively answer. Patients were overall satisfied with the intervention.

Finally, the last aim of this project was to prevent patients from treatment delays when increased anxiety, distress, confusion about treatment options or lack of knowledge prevents them from making a truly informed choice. This was achieved through the telephone communications which sought to reduce anxiety, answer questions, clarify information and focus on patient identified problems so that a new level of self-efficacy could be realized.

Interpretation

The implementation of this QI project was successful in achieving its 4 primary aims. Although the number of participants was small, the results demonstrate a statistically significant improvement in anxiety for patients after receiving the telephone communications from the GI NP. In interpreting the lack of robust results with regards to distress, one explanation includes the complex array of symptoms; emotional, physical and social, that cause distress and the subjective way in which a patient may interpret this from week to week. It is also impossible to account for confounding factors which may impact upon the subjective distress a patient may experience, such as was the case with our two patients whose distress increased prior to the start of care. One example of this might include a hospitalization for an acute medical illness that

requires a patient to be away from work, home and family. Or, an unfortunate discovery of metastasis which changes a treatment plan from curative to palliative.

This lack of robust results with regards to distress may be explained by the complex array of symptoms, emotional, physical and social that can cause distress and the subjective way in which a patient may interpret this from week to week.

In addition to the effect on anxiety, the telephone communications were successful in generating an overall satisfaction (100%) with the phase of cancer care between GI Cancer diagnosis and the start of care. In general, patients in this time frame fall into a gap where while waiting to officially start chemotherapy treatment, they are not connected to all the consultative and educational services that active patients receive. This places them at a disservice and at risk for increased anxiety and distress. By initiating phone communication throughout this time frame we were able to increase patient connectedness further enhancing a trusting relationship and increasing satisfaction with care. The increased patient satisfaction has the potential to generate revenue as patients refer family or friends to the clinic for care based on their positive experience.

Finally, of the 16 patients that were part of this QI project, none of them had their treatment delayed on the day in which they had their appointment to sign consent and initiate chemotherapy. The significance of this stretches beyond the patient and can have operational and financial impact. The patient often cannot afford further delay in terms of overall survival, as cancer progression can happen quickly while waiting for chemotherapy to begin. A delay in chemotherapy has a significant impact on the clinic in terms of shifting appointments in an already overburdened infusion schedule. The financial impact to the patient, in terms of co-pay, travel expenses and parking, as well as impact to the healthcare industry when another visit is

needed to complete consent can be overwhelming. Although this project was small, we were able to demonstrate the potential impact of the NP navigation through telephone communications and the ability to prevent delay in treatment resulting in reduction of potential interval progression and financial burden to the patient and healthcare system.

Limitations

There are limitations that were identified throughout the course of this project that affect the generalizability of this work. The first limitation relates to the small number of patients included. This institution is a large referral hospital where a number of patients come for a second opinion, or for the confirmation of a diagnosis. Many of these patients choose not to have their chemotherapy in Boston, and instead, decide to receive their care closer to home. These patients were not included as part of the QI project. Another factor impacting whether a patient was included in this project relied on whether they were signing onto a clinical trial. These patients were also not part of this QI project as they have access to another complete set of resources, including a research registered nurse they can call at any time. Finally, many patients newly diagnosed with cancer are medically unstable, particularly those with pancreatic cancer. Often, these patients are unable to initiate chemotherapy until their co-morbidities are optimized. This lengthened the time of data collection for these patients to as long as 30 days. Of the patients that were included, the majority were diagnosed with pancreatic cancer (N=12) which also limits the generalizability of this data to other GI cancers.

It was intended for the PROMIS survey and the NCCN Distress Thermometer and problem list to be initiated at the GI cancer diagnostic visit. Unfortunately, due to scheduling issues, and her own patient assignment, the GI NP was not always available to see all of the new patients at the time of their first visit. Since the number of included patients was already low, if a

patient was appropriate for the QI project and was not able to be seen on the diagnostic day, the NP would complete the screening surveys on the phone during the first telephone communication. This does impact the design as patients may not have felt as forthcoming with their answers when asked on the phone, as opposed to, completing on their own. All of the post-intervention surveys were completed in person at the start of care visit.

Conclusions

Hildegard Peplau's theory that focuses on the importance of communication to allay anxiety, provides a foundation to guide the GI NP to use telephone communications to provide support, education and guidance to the newly diagnosed GI oncology patient. This fosters the goal of decreasing anxiety through enhanced knowledge and support during a phase of oncology care when a patient is not otherwise connected to formal support services and coincides with the first three phases of Peplau's theory orientation and identification and exploitation.

Stress and anxiety play a significant role in disrupting the effective flow of communication from provider to patient regarding treatment options or prognosis. This QI project, although small in sample size, was effective in demonstrating a statistically significant reduction in anxiety scores in the time between a diagnostic visit and the start of chemotherapy by providing telephone communications between the patient and the oncology nurse practitioner. Although the same statistical significance was not demonstrated with distress scores, this is a more subjective measurement and difficult to quantitatively capture. Despite this, the returned surveys demonstrated a high degree of patient satisfaction with the phone call communications and the ability to connect with a provider from the clinic.

Treatment adherence has been shown to be linked to patient satisfaction, and improved satisfaction with clinician communication is one of the most significant predictors of improved adherence (Jacobs et al., 2017). The 16 patients included in this QI project all successfully signed informed consent on their planned start day for chemotherapy and none had delay of treatment. Though we have no comparative data, our cost/benefit analysis demonstrates that by preventing just one rescheduled patient per week there is a cost savings of over \$80,000 to the institution and potentially \$1000 for the patient. No predictions can be made about overall survival benefit by starting chemotherapy in a timely fashion.

The telephone communications played a large role in clarifying information, answering questions and expanding the general knowledge of the patient which allowed for improved self-efficacy and confidence in decision making ability regarding treatment options. This is of great significance when considering the median survival for pancreatic cancer, comprising the majority of patients in this project, from diagnosis to death without treatment is about three and one-half months and with treatment improves to eight months (Cancer Patients Alliance, 2019).

The potential implications for practice if this project were to be completed on a much larger scale are far-reaching and include impact to the patient, hospital and insurance company. Any interventions that may reduce the impact to patients who may suffer from anxiety, stress or distress, is clinically important. The nurse navigator role has long been considered a critical resource to positively impact patient's psychosocially and this has been demonstrated through this project. It is recommended that further work be done on a much larger scale in the form of an experimental research project comparing a group receiving phone call intervention and a group not receiving phone calls. Other outcomes from telephone communications that could be examined within this early phase of cancer care could include number of urgent visits to the

clinic after the first cycle of chemotherapy and number of hospitalizations for preventable side effects, among others.

Patients are diagnosed with GI cancers at increasingly higher rates and if they are medically stable, can likely begin chemotherapy treatment relatively quickly. Stress, anxiety and physical discomfort can prevent the patient from understanding and retaining information that is necessary to participate in a shared decision-making process necessary for informed consent. In addition to this, lack of connectedness to the GI oncology clinic can may hinder the development of a trusting and therapeutic relationship with the NP and the newly diagnosed GI cancer patient can help to reduce anxiety, improve patient satisfaction and lead to enhanced patient confidence when making treatment decisions, ultimately, enhancing patient care.

Funding

No funding was used or generated to support this project.

Acknowledgements

The author would like to acknowledge the overwhelming support and inspiration provided by my colleague, Dr. Ryan Nipp, and the staff of the oncology clinic who helped champion this project. In addition, Dr. Gene Harkless, DNSc, APRN, FNP-BC, CNL, FAANP, Associate Professor at the University of New Hampshire, who also took interest and endorsed this project has kindly given her time to many edits that have made this paper a success.

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Appendix A
 PROMIS Anxiety Short Form

PROMIS- Anxiety Short Form

	Please respond to each item by marking <u>one box per row.</u> In the past 7 days....	Never	Rarely	Sometimes	Often	Always
EDANX1	I felt fearful.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX2	I found it hard to focus on anything other than my anxiety.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX3	My worries overwhelmed me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX4	I felt uneasy.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX5	I felt nervous.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX6	I felt like I needed help for my anxiety.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX7	I felt anxious.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX8	I felt tense.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Scoring: $\frac{\text{(Raw sum x number of items on the short form)}}{\text{Number of items that were actually answered}}$

Raw Score	T-score	SE*
8	37.1	5.5
9	43.2	3.3
10	45.9	2.8
11	47.8	2.5
12	49.4	2.3
13	50.8	2.2
14	52.1	2.1
15	53.2	2.0
16	54.3	2.0
17	55.4	2.0
18	56.4	2.0
19	57.4	2.0
20	58.4	2.0
21	59.4	2.0
22	60.4	2.0
23	61.4	2.0
24	62.5	2.0
25	63.5	2.0
26	64.5	2.0
27	65.6	2.0
28	66.6	2.0
29	67.7	2.0
30	68.7	2.0
31	69.8	2.0
32	70.8	2.0
33	71.9	2.0
34	73.0	2.0
35	74.1	2.0
36	75.4	2.0
37	76.7	2.1
38	78.2	2.3
39	80.0	2.6
40	83.1	3.4

*SE = Standard Error

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Appendix B

Distress Thermometer and Problem List for Patients Problem List

Please indicate if any of the following have been a problem for you in the past week, including today.

Practical Problems			Physical Problems		
YES	NO		YES	NO	
		Child Care			Appearance
		Housing			Bathing / Dressing
		Insurance/Financial			Breathing
		Transportation			Change in Urination
		Work / School			Constipation
		Treatment Decisions			Diarrhea
					Eating
Family Problems					Fatigue
YES	NO	Dealing with Children			Feeling Swollen
		Dealing with partner			Fevers
		Ability to have children			Getting Around
		Family health issues			Indigestion
Emotional Problems					Memory / Concentration
YES	NO				Mouth sores
		Depression			Nausea
		Fears			Nose dry or congested
		Nervousness			Pain
		Sadness			Sexual
		Worry			Skin dry / itchy
		Loss of interest in usual activities			Sleep
		Spiritual or religious concerns			Substance use
					Tingling in hands / feet
Other Problems					

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https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf

Appendix C

Patient Satisfaction Survey -Patient Satisfaction with Cancer Care (PSCC) Scale Items

The following questions relate to your initial appointment with your oncologist and the time following that appointment until you started treatment.

	YES	NO
I felt that my health concerns were understood		
I felt that I was treated with courtesy and respect.		
I felt included in decisions about my health.		
I felt I had enough time with my doctor		
Making a follow up appointment was easy		
I received all of the services I needed.		
The doctors seemed to communicate well about my care.		
I received high-quality care from my regular oncologist.		
I received high-quality care from any specialists I saw.		
My oncologist seemed informed about the results of tests I had done		
I am satisfied with the level of care I received thus far		

Appendix C

Patient Satisfaction Survey -Patient Satisfaction with Cancer Care (PSCC) Scale Items

The following questions relate to the phone call / live visit you had with the Nurse Practitioner after your diagnostic visit to further discuss any questions or concerns that may have arisen.

	YES	NO
I received a phone call or had a live visit with the Nurse Practitioner after my appointment with the oncologist?		
During this phone call / visit, I was encouraged to talk about my personal health concerns		
My questions were answered to my satisfaction		
This phone call / visit provided information that helped me learn how to take care of myself.		
This phone call / visit helped me to understand what the next step in my care would be		
I was able to get advice I needed about my particular health concerns or questions		
I know who to contact when I have a question and how to reach them.		
This phone call / visit helped me feel more confident in how I deal with the healthcare system		
I am satisfied with the care I received		

Please describe any other comments or feedback at this time.

Adapted from: Jean-Pierre, P., Fiscella, K., Freund, K. M., Clark, J., Darnell, J., Holden, A., ... Patient Navigation Research Program Group (2010). Structural and reliability analysis of a patient satisfaction with cancer-related care measure: a multisite patient navigation research program study. *Cancer*, 117(4), 854–861. doi:10.1002/cncr.25501