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Rhaea N. Photopoulos
University of New Hampshire, Durham

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Implementing Serious Illness Conversations in a Gastrointestinal Oncology Clinic:

A mixed method evaluation of a quality improvement initiative in a Boston Hospital.

Rhaea Nicole Photopoulos, MS, MSN, APRN-BC

University of New Hampshire

Department of Nursing

Faculty Mentor: Dr. Joanne Samuels

Practice Mentor: Dr. Areej El-Jawahri

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Abstract

INTRODUCTION: Many times, advanced care planning happens too late in patients with metastatic gastrointestinal cancer, patients and families are not educated on prognostic awareness and are often not well and poorly equipped to make informed end of life decisions.

AVAILABLE KNOWLEDGE: A Serious Illness Conversation guide was developed and implemented in a Boston hospital to aid practitioners (oncology nurse practitioners and oncologists) in facilitating advanced care planning. The aim of this study was to describe provider experience with the conversation guide and understand facilitators and barriers to implementation of advanced care planning.

METHODS: The Plan Do Study Act Method of quality improvement was used for this project. In a Boston gastrointestinal oncology clinic, three medical oncologists and two oncology nurse practitioners were trained in December 2018 on use and documentation of A Serious Illness Conversation Guide. We then reviewed the electronic medical records of 121 patients with metastatic gastrointestinal cancer, with a final sample size of 72 patients, receiving their care in a solo hospital to identify documentation of ACP, as well as health care utilization outcomes. Three cohorts were chosen for this analysis: Cohort 1: 25 newly diagnosed GI oncology patients, medical records were reviewed one year prior to the Serious Illness Conversation Training of providers (N = 25); Cohort 2: Medical records were reviewed on an additional 25 newly diagnosed GI oncology patients. They were eligible if they had newly diagnosed metastatic gastrointestinal cancer, this was three months prior to implementation of the Serious Illness Conversation training (N = 25); and the final Cohort, number 3: was a consecutive medical record review of 25 newly diagnosed patients with metastatic gastrointestinal cancer of the same trained 5 providers. This groups chart were reviewed three months after implementation of the training (N=25). We examined rates of ACP documentation and health care utilization (ED visits, hospitalizations,

ICU admissions, code status, and ACP documentation and hospice use) in these cohorts. Literature review and listserv query were conducted to identify serious illness conversations.

INTERVENTION: Serious Illness Conversation Training was performed for each individual provider. Post training for 3 months, January 2019 - March 2019, weekly individual support was given to the 5 providers to reinforce workflow and documentation.   Individual interviews were conducted post training in addition to chart reviews at 3 separate time points.

RESULTS: We enrolled 5 clinicians (3 medical oncologists and 2 oncology nurse practitioners) working in Gastrointestinal Oncology for Serious Illness Conversation Training. A chart review was performed on newly diagnosed patients with GI oncology

There were no differences between groups from time of diagnosis to an advanced care planning conversation. Patients in the post-intervention cohort had a shorter time from diagnosis to ACP (advanced care planning) conversation compared to those diagnosed one year prior to the intervention (B = -293.58, 95%CI -1003, 446, P = 0.407), but this was not statistically significant.

CONCLUSIONS: Training a small cohort of clinicians in Serious Illness Conversations, documentation in the EHR and coaching has aided these practitioners in implementation of formal advanced care planning that is accessible and visible. This study was conducted in GI oncology to demonstrate feasibility, barriers and facilitators to use of this guide. It also has illustrated that it is possible for earlier serious illness conversations leading to more informed advanced care planning.

Keywords: advanced care planning interventions, advanced cancer, goals of care discussions, oncology nurses, oncology nurse practitioners, oncologists, serious illness conversations.

Global Problem

In the absence of serious illness conversations (SIC) and advanced care planning (ACP), patients with stage IV gastrointestinal cancers are often the recipients of crisis driven, aggressive care at the end of life. Frequently, these cancers are diagnosed at stage IV and carry less than a 2-year survival rate. Sometimes, patients with advanced gastrointestinal cancers are at higher risk to receive aggressive care as the landscape of newer treatments emerge. Unfortunately, less than a third of patients with metastatic gastrointestinal cancers reported a SIC with their clinician upon diagnosis or at the first oncology visit. Often the first end of life discussion occurs within a month of death (Paladino et. al., 2019).

Serious illness conversations are those patients, family, practitioner discussions which include conversations around hopes and wishes for the future, goals of treatment, (ACP) well as end-of-life (EOL). In 2015, a landmark study by Dr. Jennifer Temel and colleagues at Massachusetts General Hospital Cancer Center (MGH), showed that integrating palliative care and ACP planning early in the course of illness for patients with advanced gastrointestinal cancer led to improvements in patient quality of life and mood. Patients also reported a more accurate understanding of their illness and prognosis and received less aggressive care at the end of life (Temel et al., 2015).

Timely consideration of palliative care (planning that happens early and often in addition to symptom management), which encompasses serious illness conversations, is imperative for those living with a serious illness. Therefore, it is critical that oncology providers not only know how to offer anti-cancer therapy, they also need to be versed in providing primary pallia-

tive care. Patients who are cared for by providers who have confidence with palliative care skills

not only experience improves outcomes, but also have prognostic clarity around their illness and

goals, which leads to better EOL outcomes. We need future strategies to train and prompt ad-

vanced car planning for the seriously ill patient and families.

Local Problem

In 2015, MGH senior leadership, as part of a hospital wide quality improvement initia-

tive, developed The Continuum Project. This QI initiative was to train all specialties and prima-

ry care practitioners to learn how to have serious illness conversations with the goal of enhancing

the provision of care for patients and their families confronting serious and imminently terminal

diagnoses. The Serious Illness Conversation Project builds on the idea that these discussions

should be an ongoing process that evolves throughout the patient's illness and informed by their

clinical course. Using a train, the trainer model, it was determined that each disease specialty

was responsible for carrying the project's vision forward in their own units. This report summa-

rizes the work completed on this project in the Gastroenterology cancer clinic at MGH.

Available Knowledge

Gastrointestinal (GI) cancer is an umbrella term that defines cancers of the esophagus,

stomach, gallbladder, biliary tract, liver, pancreas, small intestine and bowel (large intestine,

colon and rectum) and anal cancer. Esophageal, pancreatic and colorectal cancer were in the top

ten leading causes of cancer related deaths in the United States in 2018 with pancreatic cancer

holding the lowest five-year survival rate of any solid tumor (8 percent) (ACS 2019). The medi-

an survival for patients with untreated, locally advanced, unresectable pancreatic cancer can be 8 to 12 months and only 3 to 6 months for those with metastatic disease at diagnosis.

In the current modern era of chemotherapy, we have achieved the best outcomes to date with chemotherapy. Often patients are living well beyond the predicted 11.1-month median survival date. While patients receiving chemotherapy generally report better overall quality of life, extended survival with chemotherapy does not always correspond to reduced symptom burden. Because of the anatomic location of the pancreas in the central abdomen at the root of the mesentery, most patients suffer with a high symptom burden that requires management of potential issues such as pain, intractable nausea, anorexia, depression, anxiety, biliary obstruction, gastric outlet obstruction, ascites, and venous thromboembolism.

The Institute of Medicine report, *Dying in America,* (2015) discussed patients experience at the end of life as having poor symptom control, frequently needing medical visits and an overwhelming burden of responsibility for families. According to the American Medical Association, Advanced Care Planning is a way to honor patient directed choices and encourage a shared decision model for the patient and clinician to achieve together (Advanced Care Planning, AMA, 2019). Lastly and most importantly, early discussions of patients' goals have been associated with improvement in patients' quality of life and receipt of less aggressive medical care at the EOL, that is likely more value-concordant for both patients and families. The care with detailed planning is care that can be consistent with an individual patient's goals but is often not addressed and patients are exposed to care that is inconsistent with their wishes (Bernacki/ Block JAMA 2014). Unfortunately, advanced care planning is rarely occurring, and it is occurring too late in the illness trajectory.

The patient and provider can move through a short list of questions that create an assessment of what is most important to the patient. While keeping the focus on the patient's prognostic awareness and with an end goal to understand the patient's values, fears and wishes. This guide was adapted and utilized as the foundation for improving serious illness conversations in gastrointestinal oncology patients and to guide clinician training and workflow.

Use of a tool to guide clinicians and patients through shared goals of care was found to be very beneficial. The patient and provider team decide when it is time to shift from anti-cancer therapy to best supportive care (Bakitas et al., 2017). Multiple models exist, like Vital Talk and Respecting Choices but these specific programs have not been formally evaluated or disseminate. There is inadequate structural support for advanced care planning, as a standard documentation system is absent for providers. Especially in GI malignancies that become metastatic, there is not a current roadmap to help providers and patients a patient centered philosophy as they become more ill. There is a belief that physicians should be the drivers of these conversations and decisions. There is a lack of data on the appropriate timing of these conversations and the collaboration between oncologists, oncology nurses and oncology NPs around ownership of these conversations (Cohen & Nirenberg, 2011).

A more in-depth review of the literature illustrates that patients and families have a preference of providers to be the drivers of advanced care planning discussions. There is still a lack of clarity around the best timing of these conversations as the inappropriate time could diminish hope and be disruptive to a therapeutic process and clinical patient relationship (Leblanc, Nickolich, El-Jawahri, & Temel, 2016). The literature identifies themes of major gaps in communication between providers, patients and their families. In the study by Zhang et al., (2009), only

31% of patients with advanced cancer were having early discussions about end of life care with their oncology provider. In another study, approximately 70% of Americans were open to discussing advanced care planning if prompted (Eidsness, Schellinger, Young,& Bennett, 2008; Jackson, Rolnick, Asche, & Heinrich, 2009).

Early conversations to clarify values and beliefs is most helpful to take place when a patient is initially diagnosed with metastatic disease. These early conversations can be built upon for ongoing deeper discussions about prognosis, wishes and care at the end of life. Having early conversations and often, allows the patient and family peace around decisions and subsequent time to focus on quality of life and planning. This type of planning also allows a standardized approach that can be tailored to all populations of patients despite differences, whether they are cultural, religious, psychological or patients with low health literacy.

Ahluwalia et al., (2015) were able to illustrate that documented early advanced care planning in a population of veterans was associated with lower rates of acute care at the end of life. A mixed-methods summative evaluation by Bakitas et al., (2017) revealed that in a population of 57 patients with either lung or gastrointestinal cancer and 20 caregivers, which 80% were spouses, had a high degree of satisfaction with the patient decision aid used. The tool allowed patients to look ahead at choices for medical care when seriously ill. The participants felt empowered, were privy to treatment options and wanted (Bakitas et al., 2017) to take part in advanced care planning. Another similar study revealed that the intervention group of patients who were trained on QPL related topics (question prompt list) and their oncologists who received formal communication training were three times more likely to ask about prognosis (Rodenback et al., 2017). There were 140 topics for potential discussion in the intervention group, which was on-

cologist and patient dyad. 99.3% of the topics were discussed with the oncologist (Rodenback et al., 2017). The three most common barriers to advanced care planning were the patient's lack of readiness and acceptance; the physician is rushed and staff discomfort around the topic (Zhou, Stoltzfus, Houldin, Parks & Swan. 2010).

Teaching interventions for the oncologist and patient, can be a way to discuss worsening cancer and can be instrumental for the patient. Patients who were given questions prior to their visits and the oncologist, who was trained in communication around advanced care planning, showed an improvement in the patient-provider communication (Rodenback et al., 2017).   Advanced care planning soon after a metastatic cancer diagnosis helps patients and families focus on decisions that decrease burdensome care, hence improving quality of life. Education and exposure programs like Looking Ahead: Choices for Medical Care when you are Seriously Ill (Bakitas et al., 2017) are patient decision aids that empower patients.

The literature reveals that learning how to have early advanced care conversations will benefit the care of the patient and their provider. The body of evidence is applicable and generalizable to a population of patients with advanced cancer and their oncology providers. Knowing when to start conversations and planning is a topic of intense focus currently. Movement toward this shift in communication is limited by the lack of identifiable formalized pathways to have these conversations and structured developed guides. The nuance of this skill keeps the focus on the patient and respect for their process. The lack of a patient's curiosity and the oncologists coping may limit transparency and movement toward these discussions (Bernacki, et al., 2019).

Rationale

The foundation of this DNP QI Project utilized the Diffusion of Innovation Theory as the guiding theoretical framework. This theory is one of the oldest social science theories dating back to 1962 (Rogers, 2003). Its original construct was to explain how over time an idea gains adoptability and spreads through a specific population. The result of this saturation is that people, as part of a social system, adopt a new idea, behavior or product. The key to adoption is the person using the idea must perceive it as innovative. Adoption of something new is a process where some adopt it easily and others do not. Researchers have identified early adopters of innovation are different than people who adopt later down the line. There are five established adopter categories, innovators, early adopters, early majority, late majority and laggards (Rogers, 2003). Innovators are interested in new ideas and are considered risk takers. They often do not need appealing to be convinced to take a risk and try something new. Early adopters are leaders and do well with structured communication in the form of how-to manuals. Early majority is the most likely represented of the general population. They are rarely in leadership positions and need to see evidence before implementing innovation. The final two categories are late majority and laggards where skepticism, tradition and conservative beliefs hold these populations back.

Specific Aims

1) To increase the documentation rate of ACP documentation by 10% by the end of the project in March 2019.

2) To examine the impact of training GI oncology clinicians on the use of the serious illness conversation guide on patients' rates of hospitalization, ACP documentation and hospice utilization.

3) To qualitatively examine facilitators and barriers to using the serious illness conversation guide in clinical practice.

Context

The setting was Massachusetts General Hospital Cancer Center, Outpatient Gastrointestinal Cancer Clinics. The GI clinic is in an outpatient setting that is adjacent to the main hospital. This is a private clinic that has 29 single examination rooms, where patients and their families come for evaluation. Patients who present to this clinic are on active chemotherapy for a gastrointestinal malignancy. They are often seen by their nurse practitioner or oncologist on average three times per month for therapy and symptom management. They receive chemotherapy/immunotherapy and or symptom management in the same clinic on an adjacent suite. Three medical oncologists and two oncology nurse practitioners were chosen to be part of this project as early trained adopters of the Serious Illness Conversation training and implementation.

Intervention

Ariadne Labs is a joint center of innovation between Brigham and Women's Hospital and the Harvard T.H. Chan School of Public Health. This center for innovation has brought together experts in palliative care, who in 2011 developed a scalable model that systematizes a guide to structure the Serious Illness Conversation Template. The questions in the guide focus on hopes and worries for the future. The guide specifically allows the provider to ask open ended questions that can be tailored to each patient. The aim of training providers on serious illness communication is to help providers to have a deeper quality and meaning conversation with the intention that the patient and clinician anxiety around initiating these emotionally difficult conver-

sations should diminish. The customizable guide or script helps to initiate planning when one is

diagnosed with a life-threatening illness. The guide avails clinicians to a structured conversation

algorithm, where it starts with asking permission to open the discussion to a more intimate look

at patients and families. There is a concern that talking about end of life goals/advanced care

planning can potentially cause more anxiety and lessen hope. Block and Bernacki (2014), bring

to light and reference many articles that indicate earlier advanced care planning does not harm

patients, rather create more peace in patients and families lives.

Two oncology nurse practitioners and five medical oncologists underwent a 3-hour training on

how to utilize the Serious Illness Conversation guide in their practice. This APRN was the train-

er for these providers. In addition, this APRIN prepared a detailed case to be utilized as a script

for the providers about a complex gastrointestinal oncology case. One that encompassed med-

ical, psychosocial and spiritual complexity as it related specifically to a patient with metastatic

gastrointestinal cancer who had a likely prognosis of 1-2 years. The goal in training this group

of 5 providers was to teach them the tools to then have an earlier goals and values conversations

with their patients.

The 5 GI oncology providers (3 GI Medical Oncologist's and 2 GI Oncology Nurse Prac-

titioner's) underwent a 3-hour training in December 2018. The training was outlined as such:

Reflection (10 min), an introduction and description of how a Serious Illness Conversation dif-

fers from a goals of care discussions/end of life planning, the minutiae of the Serious Illness

Conversation Guide, how one would Implement the Serious Illness Conversation Guide in clini-

cal practice, Discussion of Prognostic Awareness, learning how to Document in Epic (35 min-

utes). Then a 30-minute role play demonstrating how to use the Serious Illness Conversation

Guide. The 5 providers were given a 15-minute break before then doing a 90-minute skills prac-

tice in their small group. Practice with the serious illness conversation guide was used during

role plays. Then the last 15-minute break was given before a wrap up discussion on how these 5

clinicians would implement a Serious Illness Conversation into their clinical practice, including

documentation into the EHR. In the three months after training, this APRN was present in the

weekly clinics of the GI oncologists and NPs to answer questions around utilization of the guide

and subsequent documentation of ACP in the EHR. There was a daily check in with providers to

prompt them to identify patients who are appropriate for a conversation using the guide. Func-

tioned as a peer-educator around the use of the Electronic Health Record (EPIC).

The proposed timeline that helped actualize this DNP project started with project ap-

proval in mid-October 2018. The identified cohort of GI Oncologists and NPs signed up for Se-

rious Illness Conversation Training in November 2018.   Chart reviews were performed on 25

patients newly diagnosed with a metastatic GI Cancer during the time period of 1-year pre-inter-

vention from June 2017 - August 2017. Training for the NPs and MDs took place in December

2018. Peer Educator support was provided from December to March to help with coaching, us-

ability of the tool and integration. In March 2019, provider interviews were conducted in order

to gather qualitative data, in addition to final chart reviews on 50 patients pre and post training of

providers. Results were analyzed in mid - March of 2019 and the final report submitted on May

9, 2019 to UNH to fulfill requirements of the DNP. See Appendix A for Project Timeline.

Study of the intervention

Interviews were performed a month after the training in January 2019 to assess percep-

tions of the Serious Illness Conversation training. An interview script was composed to help

gather information about positive and negative perceptions in addition to facilitators and barriers

to implementation of the conversation and documentation into practice. We conducted qualita-

tive interviews with 3 GI oncologists and 2 GI oncology nurse practitioners to assess their over-

all perception of the Serious Illness Conversation Training, and their perceptions of barriers and

facilitators to implementing ACP discussions in their clinical practice. All interviewed were

conducted within 1 month of completing the Serious Illness Conversation training. We recorded

and transcribed the interviewed and thematically analyzed the content by two independent

coders. Discrepancies were resolved by consensus discussion and high reliability was achieved

between coders.

Measures

- In the quantitative data analysis, the variables compared were time to diagnosis to chart

  review or death, time of diagnosis to advanced care planning conversation, time of diag-

  nosis to follow up (death or to the last chart review), hospice referral. Retrospective chart

  reviews at 3 time points for a total of 72 patients (25 in each cohort). Provider charts

  were reviewed consecutively, and all consults were excluded. Documentation of ACP:

  we reviewed and queried the electronic medical record to identify any documentation of

  goals-of-care discussions or ACP conversations occurring in the inpatient or outpatient

  setting

- Hospitalization: we reviewed and queried the electronic medical record to determine the

  number and duration of hospitalizations during the study period for cohorts 1, 2 and 3.

- ICU admissions: we reviewed and queried the electronic medical record to identify patients in cohort 1, 2 or 3 had any ICU admissions as part of their hospitalization.

- ED visits: we reviewed and queried the electronic medical record to capture ED visits for all three cohorts during the study period.

- Code status documentation during admission: we reviewed and queried the electronic medical record to understand coded status during a hospitalization.

- Hospice utilization: we reviewed and queried the electronic medical record to determine where hospice was being provided for those that were referred. Inpatient or home.

Analysis

Data was formatted in a password protected excel file and the data pulled into Stata for data analysis. Three cohorts were described as Cohort 1= 1-year pre intervention, Cohort 2= 3 months pre intervention and lastly Cohort 3 = 3 months post the intervention. Frequency statistics were generated for each of the categories.

Ethical Considerations/Protection of Human Subjects

This project had approval by MGH, The Continuum Project, to collect data as part of a hospital wide quality improvement initiative. All electronic files containing personal patient information were password protected to prevent access by unauthorized users. There were no ethical concerns, data was de-identified and consecutive newly diagnosed patients receiving their

care during the three time points identified during the study (1 year pre/1st 3 months of diagno-

sis, 3 months pre and 3 months post intervention) The chart reviews were conducted as part of a

quality improvement project, training and implementation of The Serious Illness Conversation

Guide (Ariadne Labs), in GI Oncology. Clinician interviews post training were also conducted

as part of the quality improvement project within the context of training providers how to access

and utilize The Serious Illness Conversation Guide project at Massachusetts General Hospital

Cancer Center, Gastrointestinal Oncology clinic.

Results

Table 1. Summary Data

	Cohort 1 - 1 yr pre	Cohort 2 - 3 months pre	Cohort 3 - 3 months post
Age mean(range)	67 (39-85)	67 (45-92)	68 (52-86)
Gender	46% F 54% M	50% F 50% M	46% F 54% M
Disease (pancreatobiliary, colorectal, gastroe-sophageal)	1= 50% 2= 38% 3= 12%	1= 33% 2= 33% 3= 33%	1= 42% 2=45% 3= 12%
Lines of Chemotherapy median (range)	1 (0-2)	1 (0-2)	1 (0-3)

(Categorical Disease - 1= Colorectal, 2= Pancreatic, 3=Gastro-esophageal)

Table 2. Descriptive Results

	Cohort 1 - 1 yr pre	Cohort 2 - 3 months pre	Cohort 3 - 3 months post
ACP Conversation (Y/N)	No - 100% of patients	Yes 20 % of patients.	Yes 17% of patients
Time from dx to ACP conversation	No observations	62.8 days	52.25 days
Total Hospitalizations	54% =1 46% = 2	63%= 1 38%= 2	34% = 1 67% = 2
ICU Admissions	No observations	No observations	1 observation
Code status discharge from first admission	92% full code	100% full code	85 % full code
Code status last discharge	100% = Full Code	100% = Full Code	85% Full Code
Hospice Referral	77%	22%	100%

Analysis of clinician's interviews used a content analysis approach. Interviews were coded and analyzed using NVivo 11 software to identify and extract major and minor themes. Two coders independently reviewed the qualitative interviews and categorized the data into broader issues and themes. Specifically, the analysis was focused on 1) overall clinician's perception of the serious illness conversation guide training and its use in practice, 2) clinicians impressions of barriers and facilitators to implementing the serious illness conversation guide in clinical practice and 3) and feedback recommending for future implementation in the be MGH Cancer Center for all disease centers.

Overall, the intention to evaluate the effect the training had on the clinicians and subsequent implementation of the Serious Illness Conversations into practice yielded awareness and exposure to a new way of communicating. The PDSA cycle in this process was successful in that it provided information that will inform future training and implementation cancer center wide. It is difficult to compare the results of this quality improvement project with others due to lacking evidence on implementation of advanced care planning, specifically Serious Illness Conversation communication.

As observed in the data, formally training of individuals potentially could have contributed to early usability of the tool. There were no Serious Illness Conversations present a year before the intervention with no observable documentation in Cohort 1. There were no differences between groups one and 2 from time of diagnosis to an advanced care planning conversation. Patients in the post-intervention cohort had a shorter time from diagnosis to ACP(advanced care planning) by approximately 10 days sooner with a documented conversation compared to those diagnosed one year prior to the intervention where there were no observable conversations ($B = -293.58$, 95%CI -1003, 446, $P = 0.407$). This data is not statistically significant but may be relevant for future work.

Limitations

The data collected for this project only is a small sample of the larger volume of this GI oncology clinic. The early trained providers only represent a quarter of the practice. These early trained providers had the benefit of also having peer support for a three-month period of time. This may have also accounted for more conversations with the study period. Code status and

hospice utilization was hard to evaluate given most of these patients were newly diagnosed with a GI malignancy. There was not a patient arm where patients were able to prompt their provider with preparatory materials that would have prompted providers to consider the Serious Illness Conversation. There was no consideration of clinician knowledge base and how much exposure they had to prior advanced care planning training. One major limitation was the variability of the clinician's workflow and the time constraints in having these conversations. This new workflow was layered onto an already busy clinic flow. These providers were also very interested in learning more about advanced care planning and may have been more passionate to document and try these conversations out with their patients.

Nurse practitioners were focused on the benefit of the tool and how to implement it in to their workflow as they were not making major treatment decisions. There were differing philosophies between MD and NP groups on the timing of when to initiate the serious illness conversation and which role group was responsible for initiating these discussions. There was a level of fear that if there was a serious illness conversation documented, that it gave any provider the liberty to make decisions for that patient. The primary oncologists still wanted to be the ultimate decision makers with their patients.

Interpretation

There was relevance that serious illness conversations are necessary and could be instrumental in decreasing the use and exposure of highly medicalized care at the end of life for patients with terminal gastrointestinal malignancies.

The provider knowledge and communication skills around advanced care planning can help patients and their families ask appropriate questions that could open the door for more

meaningful goal focused dialogue and have a much more synergistic and open relationship with their providers and their own families/communities. This is a seismic shift from the current state of advanced care planning, where isolated decisions are made about code status or to stop chemotherapy in the setting of progressive disease.

Implications for future research would be to develop a practice workflow that identifies at risk populations of cancer patients for early conversations. This new workflow would allow for repeated discussions that ideally start early in one's diagnosis. This would give the patient and their family time for ongoing reflection and discussion, which could lead to patient and family focused medical interventions in advanced cancer.

Conclusions

The aim with of this project was to elicit behavior change in an area of healthcare that is in desperate need of improved communication. Training GI Oncologists and GI oncology nurse practitioners has helped uncover a fragmented process for taking care of seriously and often terminally ill cancer patients. Often the philosophy and goal is to follow a path to cure disease and along the way the patient's wishes, goals and hopes become disconnected from treatment planning and goal concordant care is sidelined.

The gastrointestinal oncology population is complex with disease survivability that is ever changing and lengthened with newer treatments in the pipeline. Clinician prognostication becomes a challenge for providers when working with motivated and deeply committed patients and their families. Patients are often living longer because of more detailed cancer genetics on mutational status and the potential for clinical trial eligibility. This population of patients are living much longer with many complicated palliative care needs, as the sequelae of the disease is

often what is left to manage. Patients outliving their expected prognosis depended on the specif-

ic disease (colon, pancreatic, gastric) also are burdened with more secondary issues that not orig-

inally predicted. For example, a metastatic colon cancer patient who has lived a decade, now

dealing with brain metastases and having to make decisions around capacity and end of life

wishes. It was empowering to train a smaller cohort of providers, as they were eager to learn the

skills to improve patient care and be exposed to a tool that would also give the clinician the abili-

ty to self-reflect.

The goal of this project was to assess the impact training had for each of the GI oncology

clinicians on the use of the serious illness conversation guide while looking at the timing of ACP

conversations from time of initial diagnosis in parallel. In addition, other metrics were also

evaluated; ED utilization, rates of hospitalization and hospice enrollment. The defined metrics as

determined as a template for reviewing charts, combined with an understanding of the facilitators

and barriers to using the serious illness conversation guide in clinical practice helped understand

all the variables and factors that contribute deeply to a patient's care.

In having providers learn a pedagogical framework to these conversations, they were able

to experience a new type of learning that is necessary to improve a skill. Textbook learning, con-

ferences or even web-based learning would not have been effective. These clinicians were able

to observe serious illness conversations, practice them while being observed and then were given

real time feedback on how to hone the language to their own for implementation. There was an

organic process that happened with this group of providers. The deliberateness of keeping

everyone involved in a small group and then being able to see one another in the clinical setting

for 3 months post the training, really instilled a feeling of change and possibility. That the possi-

bility and opportunity was there to then avail their patients of this new way of communication and formal documentation. Oncologists were able to share their deep biases around implementation of this more structured communication process and nurse practitioners were able to identify that they needed more from their collaborating physicians in terms of prognostic awareness and for them to be initiators of early conversations in a patient's disease trajectory. The nurse practitioners felt the need to have these conversations in place early to better support the very ill patients and their families they are so intimately involved with.

In this GI oncology group, to understand the barriers to implementing this much needed planning was paramount to move forward with culture change. One where patients wishes and conversations from the start of a diagnosis, to have a road map with a patient. One that encompasses the medical, psychological and spiritual components of a person. The study period was an isolated time point that helped to illustrate that this work is implementable and will take more systematic thinking on how to formally implement it.

To illustrate the importance of this work. There was a very poignant study that was just recently published in *JAMA* internal medicine and *JAMA oncology* in March 2019. The four-year randomized control trial from 2012 - 2016 of the Serious Illness Care Program, developed by Ariadne Labs, was tested at the Dana-Farber Cancer Institute. The study looked at 91 oncologists, nurse practitioners and physician assistants partnered with 278 cancer patients. Half the patients took part in the Serious Illness Care program, while half in the control group received standard of care. The study showed that quality earlier conversations patients had with their providers, led to reduction in anxiety and depression by 50%. The study did not evaluate the de-

tails of the conversations and it did not impact survival rates. This study is the first using Serious

Illness Conversations and the results of a structured communication system.

Provider knowledge and communication skills around advanced care planning can help

patients and their families ask appropriate questions that could open the door for more meaning-

ful goal focused dialogue and improved outcomes for patients and their families. This way of

communicating could have a synergistic effect on the healthcare system, leading to a shift poten-

tially in care that is driven by cost and disparity. To care that is driven by early discussions

around what a patient would want for his or her care. This is a seismic shift from the current

state of advanced care planning, where isolated decisions are made about code status or to stop

chemotherapy in the setting of progressive disease.

The sustainability of this quality improvement intervention and implementation ultimate-

ly depends on integration of this specific communication tool into the cancer center wide and

larger hospital system. Given that this is a mission driven goal for the hospital that will be

tracked over time by quality metrics, it is probable that this will become an integrated and sus-

tainable process for patients and providers.

Implications for future research would be to develop a practice workflow that identifies at

risk populations of cancer patients for early conversations. This new workflow would allow for

repeated discussions that ideally start early in one's diagnosis. This would give the patient and

their family time for ongoing reflection and discussion. This could lead to patient and family

focused medical interventions and decreasing exposure to highly medicalized care at the end of

life for patients with terminal gastrointestinal malignancies.

Role of the Funder/Sponsor

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References

Advance Care Planning. (2019). Retrieved from https://www.ama-assn.org/delivering-care/

ethics/advance-care-planning.

Bernacki, E., Block, S.D.; American College of Physicians High Value Care Task Force:

Communication about serious illness care goals: A review and synthesis of best practices.

JAMA. 2014; 174:1994–2003.

Bernacki, R., Paladino, J., Neville, B. A., Hutchings, M., Kavanagh, J., Geerse, O. P., . . . Block,

S. D. (2019). Effect of the Serious Illness Care Program in Outpatient Oncology. *JAMA*

Internal Medicine. doi:10.1001/jamainternmed.2019.0077.

Brohard, C. Initial efficacy testing of an autobiographical memory intervention on advanced care

planning for patients with terminal cancer. *Oncology Nursing* Forum. 2017 Nov 1;44(6):

751-763.

Bruera, E., Hui, D. Integrating supportive and palliative care in the trajectory of cancer:

Establishing goals and models of care. *Journal of Clinical Oncology.* 2010; 28:4013–

4017.

Coach, Don't Just Teach - Communication Coaching for Clinicians. (2019, March 28). Retrieved

from https://catalyst.nejm.org/coach-teach-communication-coaching.

Chan, A., Chien, I., Moseley, E., Salman, S., Kaminer Bourland, S., Lamas, D., … Lindvall, C.

(2019). Deep learning algorithms to identify documentation of serious illness conversa-

tions during intensive care unit admissions. Palliative Medicine, 33(2), 187–196. https://

doi-org.unh.idm.oclc.org/10.1177/0269216318810421

Colorectal cancer statistics. (2018, September 12). Retrieved from https://www.wcrf.org/dietand-

cancer/cancer-trends/colorectal-cancer-statistics

Committee on Approaching Death: Addressing Key End of Life Issues; Institute of Medicine.

>   Dying in America: Improving Quality and Honoring Individual Preferences Near the End

>   of Life. Washington (DC): National Academies Press (US); 2015 Mar 19. Available from

>   https://www.ncbi.nlm.nih.gov/books/NBK285681/ doi: 10.17226/18748.

Connors, A.F., Dawson, N.V., Desbiens, N.A., et al. A Controlled Trial to Improve Care for Seri-

>   ously III Hospitalized Patients, The Study to Understand Prognoses and Preferences for

>   Outcomes and Risks of Treatments (SUPPORT). *JAMA*. 1995;274(20):1591–1598. doi:

>   10.1001/jama.1995.03530200027032.

Costi, R., Leonardi, F., Zanoni, D., Violi, V., & Roncoroni, L. (2014). Palliative care and

>   end-stage colorectal cancer management: the surgeon meets the oncologist. *World

>   Journal of Gastroenterology*, *20*(24), 7602–7621. doi:10.3748/wjg.v20.i24.7602

Doing a Systematic Review: A Student's Guide. Angela Boland, M. Gemma Cherry & Rumona

>   Dickson (eds.). SAGE. November 2013.

Dowding, D. (2013). Best Practices for Mixed Methods Research in the Health Sciences John W.

>   Creswell, Ann Carroll Klassen, Vicki L. Plano Clark, Katherine Clegg Smith for the Of

>   fice of Behavioral and Social Sciences Research; Qualitative Methods Overview Jo Mo

>   riarty. *Qualitative Social Work*, *12*(4), 541–545.

Dying in America: Improving quality and honoring individual preferences near the end of life.

>   (2015). Washington, D.C.: The National Academies Press.

Eidsness, L.M., Schellinger, E.L., Young, S., & Bennett, J. (2008). Advance care planning. *South

>   Dakota Medicine*, Spec No. 12–18.

Emanuel, E.J., Emanuel, L.L.,The economics of dying. The illusion of cost savings at the end of

life. *New England Journal of Medicine.* 1994; 330 (8): 540 – 544. DOI: 10.1056/NE-

JM199402243300806.

Ganguli, I., Chittenden, E., Jackson, V., & Kimball, A. B. (2016). Survey on Clinician Percep-

tions and Practices Regarding Goals of Care Conversations. *Journal of Palliative Medi-*

cine, *19*(11), 1215-1217.

Geerse, O. P., Lamas, D. J., Sanders, J. J., Paladino, J., Kavanagh, J., Henrich, N. J., … Block, S.

D. (2019). A Qualitative Study of Serious Illness Conversations in Patients with Ad-

vanced Cancer. *Journal of Palliative Medicine*. https://doi

org.unh.idm.oclc.org/10.1089/jpm.2018.0487.

Gawande, Atul, author. (2014). Being mortal: medicine and what matters in the end. New

York: Metropolitan Books, Henry Holt and Company.

Information and Resources about for Cancer: Breast, Colon, Lung, Prostate, Skin. (n.d.).

Retrieved from https://www.cancer.org.

Johnson PC, Xiao Y, Wong RL, et al. Potentially Avoidable Hospital Readmissions in Patients

With Advanced Cancer. *Journal of Oncology Practice.* April 2019:JOP1800595. doi:

10.1200/JOP.18.00595.

Lakin JR, Benotti E, Paladino J, Henrich N, Sanders J. Interprofessional Work in Serious Illness

Communication in Primary Care: A Qualitative Study. *Journal of Palliative Medicine*.

January 2019. doi:10.1089/jpm.2018.0471.

Lakin, J. R., Koritsanszky, L. A., Cunningham, R., Maloney, F. L., Neal, B. J., Paladino, J., & ...

Bernacki, R. E. (2017). A Systematic Intervention To Improve Serious Illness Communi-

cation In Primary Care. *Health Affairs (Project Hope)*, *36*(7), 1258-1264. doi:10.1377/
hlthaff.2017.0219.

Mehta, A. K., Wilks, S., Cheng, M. J., Baker, K., & Berger, A. (2018). Nurses' Interest in Independently Initiating End-of-Life Conversations and Palliative Care Consultations in a Suburban, Community Hospital. *The American Journal Of Hospice & Palliative Care*, *35*(3), 398-403. doi:10.1177/1049909117704403.

Miranda, S. P., Bernacki, R. E., Paladino, J. M., Norden, A. D., Kavanagh, J. E., Palmor, M. C., & Block, S. D. (2018). A Descriptive Analysis of End-of-Life Conversations with Long-Term Glioblastoma Survivors. *The American Journal Of Hospice & Palliative Care*, *35*(5), 804-811. doi:10.1177/1049909117738996.

Myers, J., Cosby, R., Gzik, D., Harle, I., Harrold, D., Incardona, N., & Walton, T. (2018). Provider Tools for Advance Care Planning and Goals of Care Discussions: A Systematic Review. *The American Journal of Hospice & Palliative Care*, *35*(8), 1123-1132. doi:10.1177/1049909118760303.

Nickolich, M. S., El-Jawahri, A., Temel, J. S., & LeBlanc, T. W. (2016). Discussing the Evidence for Upstream Palliative Care in Improving Outcomes in Advanced Cancer. *American Society of Clinical Oncology Educational Book. American Society of Clinical Oncology. Meeting*, *35*e534-e538. doi:10.14694/EDBK_159224.

Ouchi K, Jambaulikar G, George NR, et al. The "Surprise Question" Asked of Emergency Physicians May Predict 12-Month Mortality among Older Emergency Department Patients. *Journal of Palliative Medicine*. 2018;21(2):236-240. doi:10.1089/jpm.2017.0192.

Paladino J, Bernacki R, Neville BA, et al. Evaluating an Intervention to Improve Communication

Between Oncology Clinicians and Patients With Life-Limiting Cancer: A Cluster Ran-

domized Clinical Trial of the Serious Illness Care Program. *JAMA Oncology*. March

2019. doi:10.1001/jamaoncol.2019.0292.

Pirl, W. F., Greer, J. A., Park, E., Safren, S. A., Fields, L., Wood, L., & ... Temel, J. S. (2017).

Development and evaluation of a six-day training program in supportive oncology re-

search. *Palliative & Supportive Care*, 1-6. doi:10.1017/S1478951517001092.

Rogers.E.M. (2003). *Diffusion of innovations*. New York: Free-Press.

About the SEER Program. (n.d.). Retrieved from https://seer.cancer.gov/about/

SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill

hospitalized patients: The Study to Understand Prognoses and Preferences for Outcomes

and Risks of Treatments (SUPPORT). *JAMA,* 274,1591–1598.

Temel, J.S., Greer, J.A., Admane, S., et al. Code Status Documentation in the Outpatient Elec-

tronic Medical Records of Patients with Metastatic Cancer. *Journal of General Internal

Medicine*. 2010;25(2):150-153. doi:10.1007/s11606-009-1161.

Temel, J. S., Greer, J. A., El-Jawahri, A., Pirl, W. F., Park, E. R., Jackson, V. A., . . . Ryan, D. P.

(2017). Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer:

A Randomized Clinical Trial. *Journal of Clinical Oncology, 35*(8), 834-841. doi:

10.1200/jco.2016.70.5046.

Temel, J. S., Gainor, J. F., Sullivan, R. J., & Greer, J. A. (2018). Keeping Expectations in Check

With Immune Checkpoint Inhibitors. *Journal of Clinical Oncology, 36*(17), 1654-1657.

doi:10.1200/jco.2017.76.2146.

www.uptodate.com/contents/clinical-manifestations-diagnosis-and-staging-of-esophageal-can

cer/print.

Vogel, R.I., Petzel, S.V., Cragg, J., et al. Development and pilot of an advance care planning

     website for women with ovarian cancer: a randomized controlled trial. Gynecologic On-

     cology 2013; 131 (2): 430 – 436. DOI: 10.1016/j.ygyno.2013.08.017.

Volandes, A.E., Paasche−Orlow, M.K., Mitchell, S.L., et al. Randomized controlled trial of a

     video decision support tool for cardiopulmonary resuscitation decision making in ad-

     vanced cancer. Journal of Clinical Oncology 2013; 31 (3): 380 – 386. DOI: 10.1200/

     JCO.2012.43.9570.

Zhang, B., Wright, A.A., Huskamp, H.A., Nilsson, M.E., Maciejewski, M.L., Earle, C.C., Priger-

     son, H.G. (2009). Health care costs in the last week of life: Archives of Internal Medi-

     cine, 169,480–488.

Appendices

Appendix A.   Project Timeline

	Oct	November	December	January	February	March	April
Project approval	x						
NPs/MDs Sign up for SIC training		x					
Chart reviews 1 yr pre-intervention (1st 3 mo of new dx)		x					
SIC training			X				
3-months post training, coaching and elbow support				x	x	x	
Provider interviews 3 months post training						x	
Chart reviews, 3 mo pre-training						x	
Chart reviews, 3 mo post training							x
Analysis of outcomes							x
Results presented to UNH							x

Appendix B. Serious Illness Conversations Training Case

Serious Illness Conversations
GI Oncology Case – Clinician Role

SETTING: Outpatient clinic, meeting with your oncology doctor, nurse practitioner

- 66 year old female homemaker and retired hairdresser with colon cancer.
- Resection for cure, then recurrence, on third line treatment, PS 1 -- working as an administrator.
- Husband has been to every visit and disseminates information to the family.

The goal of the discussion today is to explore wishes for future care using the Serious Illness Conversation Guide. The focus should be on values and goals for the months ahead rather than procedures and therapies.

Serious Illness Conversation
GI Oncology Case – Patient Role

SETTING: Outpatient clinic, meeting with your oncology doctor or nurse practitioner.

Appendix B

Serious Illness Conversation Guide Oncology

OPEN THE CONVERSATION

I'd like to talk about what is ahead with your illness. Would that be OK?

ASSESS PROGNOSTIC AWARENESS *What is your understanding of your illness? Looking to the future, what are your hopes about your health? What are your worries?*

SHARE WORRY *Would it be OK if we talked more about what lies ahead?*

FUNCTION: I hear you're hoping for _____ and I worry the decline we have seen is going to continue.

TIME: I hear you're hoping for _____ and I worry something serious may happen in the next few (wks/mths/yrs).

ALIGN *I wish we didn't have to worry about this.*

EXPLORE WHAT'S IMPORTANT
If your health situation worsens, what is most important to you? How much do your family or friends know about your priorities and wishes?

MAKE A RECOMMENDATION *It sounds like _____ is very important to you. Given what's important to you, I recommend ...*

DOCUMENT YOUR CONVERSATION (EPIC in the ACP module) To add to your patient note, .ACPSIL.

Appendix C. Serious Illness Conversation Guide

📄 Serious Illness Conversation Guide

Open the conversation
"I'd like to talk about what is ahead with your illness. Would that be ok?"

Assess prognostic awareness
"What is your **understanding** of your illness?
"Looking to the future, what are your **hopes** about your health?" "What are your **worries**?"

Share hope and worry
"Would it be ok if we talked more about what lies ahead?"
Function: "I hear you're **hoping** for _____ **and I worry** the decline we've seen is going to continue."
Time: "I hear you're **hoping** for _____**and I worry** something serious may happen in the next few (wks/mths/yrs)."

Align
"**I wish** we didn't have to worry about this."

Explore what's important
"If your health worsens, what is most important to you?"
"How much do your family or friends know about your priorities and wishes?"

Close the conversation
"It sounds like _____ **is very important to you.**"
"Given what's important to you, **I would recommend...**"

⊞ SIC ✎

➕ New Reading   Flowsheets ⤢

	Last Filed Value
Serious Illness Conversation	
Patient illness understanding	full awareness of prognosis - does not have a time frame in mind. ◄◄
Hopes	Live as long as possible; Be comfortable; Be independent ◄◄
Worries	Other physical suffering ◄◄
Prognostic information shared	Not discussed ◄◄
What's important to patient/family	Would like to feel better so that she can live a full life for what time she has. Would like to return to teaching. ◄◄
Recommendations	Meeting with ████████ tomorrow ▨ Encouraged to consider QOL and goals in choosing therapy. Encourage fol with Palliative as well (████) ◄◄

Appendix C – Perceptions of Serious Illness Conversations

Overarching ideas
- ■ Nurse practitioners and oncologists thought the training and tool were very beneficial.
- ■ There was differing philosophies between MD and NP groups on the timing of when to initiate the serious illness conversation.
- ■ A concern from both role groups around causing worry for patients/families by having these conversations.
- ■ Fear that seeing the documented conversation in a patient's medical record, allowed any provider to make end of life decisions. Primary teams wanted to still be primary decision makers with the patient and family.

A. **Perceptions/themes** _(NP= nurse practitioner, MD= physician)_
Positive Perceptions
1. _Mixed reviews - Some liked, some disliked, small group learning was excellent. (NP & MD)
2. Learning Framework and language to talk about SIC. (NP)
"Loved the training, thought it was great. Loved that there was a structured script to use. This training will change practice by giving me more confidence to continue the conversation." (NP)
3. Approach and Framework. (MD)
"Loved the training, thought it was great. Loved that there was a structured script to use. This training will change practice by giving me more confidence to continue the conversation." (NP)

Negative Perceptions
4. Training during clinic time less than ideal, the burden of having to be away from a clinic on a clinical day was difficult. (NP)
5. Role play anxiety.
"There was anxiety around having to share the space with peers and being watched and judged." (MD)
6. Logistics of using the guide, not knowing were to find it in the days following the training was not intuitive. (NP)
7. Clinic demands and being away from patient care. (MD)
8. Too hypothetical to use script in clinical practice. (NP)
"Least helpful, role playing and having to use an actual formalized script provided to us." (RN
B. Role Change in Practice
1. Ambiguity regarding roles in the conversations. Clinician ownership regarding initiation of the conversation.
"Role in these conversations is to be a continuer of the conversation, not the initiator." (NP)
2. Training informs language used in conversation.
"Serious Illness Conversations training taught how to be more silent during those conversations. Knowing how to disseminate prognosis not just around bad news." (MD)
3. Acknowledging difficulties in changing practice. (MD)

C. Communication

Facilitators

1. Taking responsibility for early prognostic exposure.

"More initiative from the MD about prognosis would allow the invitation to use it more." (MD)

2. Enhancing documentation quality throughout the trajectory.

"Documentation quality is excellent and should be available for every patient in each visit." (NP)

3. Substantiating, quantifying work flow.

4. Financial incentive.

5. Easy workflow.

Barriers

1. Perceived barriers to serious illness conversation implementation.

2. Patients reluctance to address the topic.

3. Logistics of integration into the workflow.

4. Patient fear and clinician discomfort in imitating these conversations.

"Patients who need it most do not want you to go there. Fear as a clinical that you will bring more worry to a patient, this is not an easy task to accomplish. The biggest challenge is to be in the moment." (NP)

6. Concern about documentation would impact acute decision making

"You do not want the module to be the decision maker for your patients, still want to the be the primary oncologist that can share in decision making." (MD)

7. Time constraints to having the conversations.

D. Success to Implementation

1.   Engaging disease groups around challenging cases.

2. Regular occurring discussions about tough cases, weekly or bi-monthly disease specific rounds.

3. Empowering various team members to initiate and continue these conversations.

4. Shifting cultural norms around appropriateness and timing (engaging disease groups) of Advanced Care Planning discussions.

      a. Review at Cancer Center Division Meetings.

      b. Quality Improvement Incentive.

      c. Pamphlets/information shared with patients upfront.

      d.

      e. Enhancing evidence regarding benefit of this approach.

Appendix D - Quantitative Data

Time from diagnosis to advance care planning:

There were no differences between groups from time of diagnosis to an advanced care planning conversation. Patients in the post-intervention cohort had a shorter time from diagnosis to ACP conversations compared to those diagnosed one year prior to the intervention (B = -293.58, 95%CI -1003, 446, P = 0.407), but this was not statistically significant.

```
. summarize age, detail

                              Age
-----------------------------------------------------------------
      Percentiles      Smallest
 1%          39             39
 5%          47             45
10%          52             47      Obs                    72
25%          60             47      Sum of Wgt.            72

50%        66.5                     Mean            67.63889
                       Largest      Std. Dev.       11.68399
75%          77             85
90%          82             86      Variance        136.5156
95%          85             87      Skewness       -.1934949
99%          92             92      Kurtosis         2.28724


. by cohort, sort: summarize age, detail

-----------------------------------------------------------------------------------------------------------------

-> cohort = 1

                              Age
-----------------------------------------------------------------
      Percentiles      Smallest
 1%          39             39
 5%          47             47
10%          49             49      Obs                    24
25%        59.5             50      Sum of Wgt.            24

50%        70.5                     Mean            67.66667
                       Largest      Std. Dev.       13.02728
75%          78             82
90%          82             82      Variance        169.7101
95%          84             84      Skewness       -.5405427
99%          85             85      Kurtosis        2.253053


-----------------------------------------------------------------------------------------------------------------

-> cohort = 2

                              Age
-----------------------------------------------------------------
      Percentiles      Smallest
 1%          45             45
 5%          47             47
10%          52             52      Obs                    24
25%        59.5             53      Sum of Wgt.            24

50%        64.5                     Mean            67.20833
                       Largest      Std. Dev.       12.42361
75%          77             80
90%          81             81      Variance         154.346
95%          87             87      Skewness        .0819938
99%          92             92      Kurtosis         2.25291
```

```
==============================================================================================
-> cohort = 3

                              Age
--------------------------------------------------------------------------
        Percentiles      Smallest
  1%           52             52
  5%           55             55
 10%           56             56      Obs                    24
 25%           60             57      Sum of Wgt.            24

 50%          66.5                    Mean             68.04167
                          Largest     Std. Dev.        9.848766
 75%          76.5             78
 90%           81             81      Variance         96.99819
 95%           83             83      Skewness         .1474753
 99%           86             86      Kurtosis         1.779145
```

.

```
    Gender |      Freq.     Percent        Cum.
-----------+-----------------------------------
         1 |         34       47.22       47.22
         2 |         38       52.78      100.00
-----------+-----------------------------------
     Total |         72      100.00
```

```
==============================================================================================
-> cohort = 1

    Gender |      Freq.     Percent        Cum.
-----------+-----------------------------------
         1 |         11       45.83       45.83
         2 |         13       54.17      100.00
-----------+-----------------------------------
     Total |         24      100.00
```

```
==============================================================================================
-> cohort = 2

    Gender |      Freq.     Percent        Cum.
-----------+-----------------------------------
         1 |         12       50.00       50.00
         2 |         12       50.00      100.00
-----------+-----------------------------------
     Total |         24      100.00
```

```
==============================================================================================
-> cohort = 3

    Gender |      Freq.     Percent        Cum.
-----------+-----------------------------------
         1 |         11       45.83       45.83
         2 |         13       54.17      100.00
-----------+-----------------------------------
     Total |         24      100.00
```

.

```
cat_disease |      Freq.     Percent        Cum.
------------+-----------------------------------
          1 |         30       41.67       41.67
          2 |         28       38.89       80.56
          3 |         14       19.44      100.00
------------+-----------------------------------
      Total |         72      100.00
```

```
-> cohort = 1
```

```
cat_disease |      Freq.     Percent        Cum.
------------+-----------------------------------
          1 |         12       50.00       50.00
          2 |          9       37.50       87.50
          3 |          3       12.50      100.00
------------+-----------------------------------
      Total |         24      100.00
```

```
-> cohort = 2
```

```
cat_disease |      Freq.     Percent        Cum.
------------+-----------------------------------
          1 |          8       33.33       33.33
          2 |          8       33.33       66.67
          3 |          8       33.33      100.00
------------+-----------------------------------
      Total |         24      100.00
```

```
-> cohort = 3
```

```
cat_disease |      Freq.     Percent        Cum.
------------+-----------------------------------
          1 |         10       41.67       41.67
          2 |         11       45.83       87.50
          3 |          3       12.50      100.00
------------+-----------------------------------
      Total |         24      100.00
```

.

```
                      Lines of Chemo
-------------------------------------------------------------
      Percentiles      Smallest
 1%            0              0
 5%            0              0
10%            0              0      Obs                  72
25%            0              0      Sum of Wgt.          72

50%            1                     Mean           .6666667
                     Largest         Std. Dev.      .6713451
75%            1              2
90%            1              2       Variance       .4507042
95%            2              2       Skewness        .78125
99%            3              3       Kurtosis       3.65625
```

.

```
------------------------------------------------------------------------------------------------
-> cohort = 1

                        Lines of Chemo
-------------------------------------------------------------
      Percentiles        Smallest
  1%            0                0
  5%            0                0
 10%            0                0          Obs                    24
 25%            0                0          Sum of Wgt.            24

 50%            0                           Mean                   .5
                              Largest       Std. Dev.        .6593805
 75%            1                1
 90%            1                1          Variance         .4347826
 95%            2                2          Skewness          .929516
 99%            2                2          Kurtosis             2.76


------------------------------------------------------------------------------------------------
-> cohort = 2

                        Lines of Chemo
-------------------------------------------------------------
      Percentiles        Smallest
  1%            0                0
  5%            0                0
 10%            0                0          Obs                    24
 25%            0                0          Sum of Wgt.            24

 50%            1                           Mean             .7083333
                              Largest       Std. Dev.        .6240935
 75%            1                1
 90%            1                1          Variance         .3894928
 95%            2                2          Skewness         .2620127
 99%            2                2          Kurtosis           2.3706


------------------------------------------------------------------------------------------------
-> cohort = 3

                        Lines of Chemo
-------------------------------------------------------------
      Percentiles        Smallest
  1%            0                0
  5%            0                0
 10%            0                0          Obs                    24
 25%            0                0          Sum of Wgt.            24

 50%            1                           Mean             .7916667
                              Largest       Std. Dev.          .72106
 75%            1                1
 90%            1                1          Variance         .5199275
 95%            2                2          Skewness         1.029599
 99%            3                3          Kurtosis         4.881023


.
```

Hospitaliza tion	Freq.	Percent	Cum.
1	36	50.00	50.00
2	36	50.00	100.00
Total	72	100.00	

```
-> cohort = 1
```

Hospitaliza tion	Freq.	Percent	Cum.
1	13	54.17	54.17
2	11	45.83	100.00
Total	24	100.00	

```
-> cohort = 2
```

Hospitaliza tion	Freq.	Percent	Cum.
1	15	62.50	62.50
2	9	37.50	100.00
Total	24	100.00	

```
-> cohort = 3
```

Hospitaliza tion	Freq.	Percent	Cum.
1	8	33.33	33.33
2	16	66.67	100.00
Total	24	100.00	

```
.
```

Code admit1	Freq.	Percent	Cum.
1	35	100.00	100.00
Total	35	100.00	

```
. by cohort, sort: tabulate codeadmit1
```

```
-> cohort = 1
```

Code admit1	Freq.	Percent	Cum.
1	13	100.00	100.00
Total	13	100.00	

```
-> cohort = 2
```

Code admit1	Freq.	Percent	Cum.
1	15	100.00	100.00
Total	15	100.00	

```
-> cohort = 3
```

Code admit1	Freq.	Percent	Cum.
1	7	100.00	100.00
Total	7	100.00	

```
. tabulate codestatusdischarge1
```

Code Status discharge1	Freq.	Percent	Cum.
1	33	94.29	94.29
2	2	5.71	100.00
Total	35	100.00	

```
.

. by cohort, sort: tabulate codestatusdischarge1

-> cohort = 1
```

Code Status discharge1	Freq.	Percent	Cum.
1	12	92.31	92.31
2	1	7.69	100.00
Total	13	100.00	

```
-> cohort = 2
```

Code Status discharge1	Freq.	Percent	Cum.
1	15	100.00	100.00
Total	15	100.00	

```
-> cohort = 3
```

Code Status discharge1	Freq.	Percent	Cum.
1	6	85.71	85.71
2	1	14.29	100.00
Total	7	100.00	

```
.
```

code status last admit	Freq.	Percent	Cum.
1	34	97.14	97.14
2	1	2.86	100.00
Total	35	100.00	

```
.
```

```
-> cohort = 1

code status |
  last admit |      Freq.     Percent        Cum.
-------------+-----------------------------------
           1 |         13      100.00      100.00
-------------+-----------------------------------
       Total |         13      100.00
```

```
===================================================================================================

-> cohort = 2

code status |
  last admit |      Freq.     Percent        Cum.
-------------+-----------------------------------
           1 |         15      100.00      100.00
-------------+-----------------------------------
       Total |         15      100.00
```

```
===================================================================================================

-> cohort = 3

code status |
  last admit |      Freq.     Percent        Cum.
-------------+-----------------------------------
           1 |          6       85.71       85.71
           2 |          1       14.29      100.00
-------------+-----------------------------------
       Total |          7      100.00
```

.

```
code status |
         at |
  discharge |
  last admit |      Freq.     Percent        Cum.
-------------+-----------------------------------
           1 |         27       77.14       77.14
           2 |          8       22.86      100.00
-------------+-----------------------------------
       Total |         35      100.00
```

.

```
-> cohort = 1

code status  |
          at |
   discharge |
  last admit |      Freq.      Percent        Cum.
-------------+-----------------------------------
           1 |         10        76.92       76.92
           2 |          3        23.08      100.00
-------------+-----------------------------------
       Total |         13       100.00
```

```
-> cohort = 2

code status  |
          at |
   discharge |
  last admit |      Freq.      Percent        Cum.
-------------+-----------------------------------
           1 |         11        73.33       73.33
           2 |          4        26.67      100.00
-------------+-----------------------------------
       Total |         15       100.00
```

```
-> cohort = 3

code status  |
          at |
   discharge |
  last admit |      Freq.      Percent        Cum.
-------------+-----------------------------------
           1 |          6        85.71       85.71
           2 |          1        14.29      100.00
-------------+-----------------------------------
       Total |          7       100.00
```

.

```
                    total hospitalization
-------------------------------------------------------------
      Percentiles      Smallest
 1%           0              0
 5%           0              0
10%           0              0       Obs                 59
25%           0              0       Sum of Wgt.         59

50%           1                      Mean          .5932203
                      Largest        Std. Dev.     .4954498
75%           1              1
90%           1              1       Variance      .2454705
95%           1              1       Skewness     -.3795361
99%           1              1       Kurtosis      1.144048
```

.

-> cohort = 1

                      total hospitalization

        Percentiles   Smallest
  1%   0   0
  5%   0   1
 10%   1   1   Obs   14
 25%   1   1   Sum of Wgt.   14

 50%   1   Mean   .9285714
                         Largest   Std. Dev.   .2672612
 75%   1   1
 90%   1   1   Variance   .0714286
 95%   1   1   Skewness   -3.328201
 99%   1   1   Kurtosis   12.07692

-> cohort = 2

                      total hospitalization

        Percentiles   Smallest
  1%   0   0
  5%   0   0
 10%   0   0   Obs   21
 25%   0   0   Sum of Wgt.   21

 50%   1   Mean   .7142857
                         Largest   Std. Dev.   .46291
 75%   1   1
 90%   1   1   Variance   .2142857
 95%   1   1   Skewness   -.9486833
 99%   1   1   Kurtosis   1.9

-> cohort = 3

                      total hospitalization

        Percentiles   Smallest
  1%   0   0
  5%   0   0
 10%   0   0   Obs   24
 25%   0   0   Sum of Wgt.   24

 50%   0   Mean   .2916667
                         Largest   Std. Dev.   .4643056
 75%   1   1
 90%   1   1   Variance   .2155797
 95%   1   1   Skewness   .9166985
 99%   1   1   Kurtosis   1.840336

.

```
                        total ED visits
--------------------------------------------------------------
        Percentiles     Smallest
 1%          0              0
 5%          0              0
10%          0              0          Obs                 72
25%          0              0          Sum of Wgt.         72

50%          0                         Mean          .0555556
                         Largest       Std. Dev.     .2306689
75%          0              1
90%          0              1          Variance      .0532081
95%          1              1          Skewness       3.88057
99%          1              1          Kurtosis      16.05882
```

.

```
--------------------------------------------------------------------------------
-> cohort = 1

                    total ED visits
--------------------------------------------------------------
      Percentiles      Smallest
 1%           0              0
 5%           0              0
10%           0              0        Obs                  24
25%           0              0        Sum of Wgt.          24

50%           0                       Mean           .0833333
                    Largest           Std. Dev.      .2823299
75%           0              0
90%           0              0        Variance       .0797101
95%           1              1        Skewness       3.015113
99%           1              1        Kurtosis       10.09091


--------------------------------------------------------------------------------
-> cohort = 2

                    total ED visits
--------------------------------------------------------------
      Percentiles      Smallest
 1%           0              0
 5%           0              0
10%           0              0        Obs                  24
25%           0              0        Sum of Wgt.          24

50%           0                       Mean           .0833333
                    Largest           Std. Dev.      .2823299
75%           0              0
90%           0              0        Variance       .0797101
95%           1              1        Skewness       3.015113
99%           1              1        Kurtosis       10.09091


--------------------------------------------------------------------------------
-> cohort = 3

                    total ED visits
--------------------------------------------------------------
      Percentiles      Smallest
 1%           0              0
 5%           0              0
10%           0              0        Obs                  24
25%           0              0        Sum of Wgt.          24

50%           0                       Mean                  0
                    Largest           Std. Dev.             0
75%           0              0
90%           0              0        Variance              0
95%           0              0        Skewness              .
99%           0              0        Kurtosis              .


.
```

```
      ICU |
 admission |     Freq.     Percent        Cum.
-----------+------------------------------------
         1 |         1        1.39        1.39
         2 |        71       98.61      100.00
-----------+------------------------------------
     Total |        72      100.00
```

.

```
-> cohort = 1

      ICU |
 admission |      Freq.     Percent        Cum.
-----------+-----------------------------------
         2 |         24      100.00      100.00
-----------+-----------------------------------
     Total |         24      100.00
```

```
-> cohort = 2

      ICU |
 admission |      Freq.     Percent        Cum.
-----------+-----------------------------------
         2 |         24      100.00      100.00
-----------+-----------------------------------
     Total |         24      100.00
```

```
-> cohort = 3

      ICU |
 admission |      Freq.     Percent        Cum.
-----------+-----------------------------------
         1 |          1        4.17        4.17
         2 |         23       95.83      100.00
-----------+-----------------------------------
     Total |         24      100.00
```

```
.

. tabulate survivalstatus

  Survival |
    status |      Freq.     Percent        Cum.
-----------+-----------------------------------
         1 |         69       95.83       95.83
         2 |          3        4.17      100.00
-----------+-----------------------------------
     Total |         72      100.00
```

```
      Survival |
        status |       Freq.      Percent         Cum.
---------------+-----------------------------------------
             1 |          24       100.00       100.00
---------------+-----------------------------------------
         Total |          24       100.00
```

```
-----------------------------------------------------------------------------------------------------------
-> cohort = 2
```

```
      Survival |
        status |       Freq.      Percent         Cum.
---------------+-----------------------------------------
             1 |          22        91.67        91.67
             2 |           2         8.33       100.00
---------------+-----------------------------------------
         Total |          24       100.00
```

```
-----------------------------------------------------------------------------------------------------------
-> cohort = 3
```

```
      Survival |
        status |       Freq.      Percent         Cum.
---------------+-----------------------------------------
             1 |          23        95.83        95.83
             2 |           1         4.17       100.00
---------------+-----------------------------------------
         Total |          24       100.00
```

.

Location of death for those who died

```
      location |
         death |       Freq.      Percent         Cum.
---------------+-----------------------------------------
             1 |           3       100.00       100.00
---------------+-----------------------------------------
         Total |           3       100.00
```

.

Hospice referral

```
   Hospice ref |       Freq.      Percent         Cum.
---------------+-----------------------------------------
             1 |           2        66.67        66.67
           GIP |           1        33.33       100.00
---------------+-----------------------------------------
         Total |           3       100.00
```

.

```
        ACP |
conversatio |
          n |     Freq.     Percent        Cum.
------------+-----------------------------------
          1 |         9       12.50       12.50
          2 |        63       87.50      100.00
------------+-----------------------------------
      Total |        72      100.00
```

-> cohort = 1

```
        ACP |
conversatio |
          n |     Freq.     Percent        Cum.
------------+-----------------------------------
          2 |        24      100.00      100.00
------------+-----------------------------------
      Total |        24      100.00
```

-> cohort = 2

```
        ACP |
conversatio |
          n |     Freq.     Percent        Cum.
------------+-----------------------------------
          1 |         5       20.83       20.83
          2 |        19       79.17      100.00
------------+-----------------------------------
      Total |        24      100.00
```

-> cohort = 3

```
        ACP |
conversatio |
          n |     Freq.     Percent        Cum.
------------+-----------------------------------
          1 |         4       16.67       16.67
          2 |        20       83.33      100.00
------------+-----------------------------------
      Total |        24      100.00
```

.

```
                         time_dx_acp
-------------------------------------------------------------
      Percentiles      Smallest
 1%          30              30
 5%          30              36
10%          36              53       Obs                  16
25%          61              53       Sum of Wgt.          16

50%        81.5                       Mean           272.4375
                     Largest          Std. Dev.      511.4101
75%         140             157
90%        1579             157       Variance       261540.3
95%        1579            1579       Skewness        2.24361
99%        1579            1579       Kurtosis       6.081129
```

```
=========================================================================================
-> cohort = 1

                       time_dx_acp
=========================================================================
no observations


=========================================================================================
-> cohort = 2

                       time_dx_acp
=========================================================================

       Percentiles      Smallest
  1%          53              53
  5%          53              54
 10%          53              59       Obs                    5
 25%          54              67       Sum of Wgt.            5

 50%          59                       Mean               62.8
                            Largest    Std. Dev.       11.58447
 75%          67              54
 90%          81              59       Variance           134.2
 95%          81              67       Skewness        .7955936
 99%          81              81       Kurtosis        2.176964


=========================================================================================
-> cohort = 3

                       time_dx_acp
=========================================================================

       Percentiles      Smallest
  1%          30              30
  5%          30              36
 10%          30              69       Obs                    4
 25%          33              74       Sum of Wgt.            4

 50%        52.5                       Mean              52.25
                            Largest    Std. Dev.       22.45551
 75%        71.5              30
 90%          74              36       Variance          504.25
 95%          74              69       Skewness       -.0107968
 99%          74              74       Kurtosis        1.079035
```

.

Time from ACP to death for those who died

```
                       time_acp_death
=========================================================================

       Percentiles      Smallest
  1%          24              24
  5%          24              35
 10%          24             137       Obs                    3
 25%          24               .       Sum of Wgt.            3

 50%          35                       Mean            65.33333
                            Largest    Std. Dev.       62.30837
 75%         137               .
 90%         137              24       Variance        3882.333
 95%         137              35       Skewness        .6823944
 99%         137             137       Kurtosis            1.5
```

```
                           time_chemo_death
-------------------------------------------------------------------
        Percentiles      Smallest
  1%          16              16
  5%          16              24
 10%          16             400        Obs                    3
 25%          16               .        Sum of Wgt.            3

 50%          24                        Mean            146.6667
                            Largest     Std. Dev.       219.4296
 75%         400               .
 90%         400              16        Variance        48149.33
 95%         400              24        Skewness        .7060496
 99%         400             400        Kurtosis             1.5
```

```
                           time_admit_death
-------------------------------------------------------------------
        Percentiles      Smallest
  1%          10              10
  5%          10              24
 10%          10             395        Obs                    3
 25%          10               .        Sum of Wgt.            3

 50%          24                        Mean                 143
                            Largest     Std. Dev.       218.3506
 75%         395               .
 90%         395              10        Variance           47677
 95%         395              24        Skewness        .7038379
 99%         395             395        Kurtosis             1.5
```

Comparative data

```
Hospitaliz |            cohort
    ation  |      1          2          3  |     Total
-----------+---------------------------------+----------
         1 |     13         15          8  |        36
           |  54.17      62.50      33.33  |     50.00
-----------+---------------------------------+----------
         2 |     11          9         16  |        36
           |  45.83      37.50      66.67  |     50.00
-----------+---------------------------------+----------
     Total |     24         24         24  |        72
           | 100.00     100.00     100.00  |    100.00

        Pearson chi2(2) =    4.3333   Pr = 0.115
```

.

```
     Code |
   Status |            cohort
discharge1 |      1          2          3  |     Total
-----------+---------------------------------+----------
        1  |     12         15          6  |        33
           |  92.31     100.00      85.71  |     94.29
-----------+---------------------------------+----------
        2  |      1          0          1  |         2
           |   7.69       0.00      14.29  |      5.71
-----------+---------------------------------+----------
    Total  |     13         15          7  |        35
           | 100.00     100.00     100.00  |    100.00

        Pearson chi2(2) =   1.9580   Pr = 0.376
```

.

```
     code |
status at |
discharge |            cohort
last admit |      1          2          3  |     Total
-----------+---------------------------------+----------
        1  |     10         11          6  |        27
           |  76.92      73.33      85.71  |     77.14
-----------+---------------------------------+----------
        2  |      3          4          1  |         8
           |  23.08      26.67      14.29  |     22.86
-----------+---------------------------------+----------
    Total  |     13         15          7  |        35
           | 100.00     100.00     100.00  |    100.00

        Pearson chi2(2) =   0.4155   Pr = 0.812
```

.

Total hospitalizations

. regress totalhospitalization i.cohort

```
      Source |       SS          df        MS         Number of obs   =        59
-------------+----------------------------------       F(2, 56)        =     11.19
       Model |  4.06466909        2   2.03233454       Prob > F        =    0.0001
    Residual |   10.172619       56   .181653912       R-squared       =    0.2855
-------------+----------------------------------       Adj R-squared   =    0.2600
       Total |  14.2372881       58   .245470485       Root MSE        =    .42621
```

```
 totalhospi~n |      Coef.   Std. Err.      t    P>|t|     [95% Conf. Interval]
--------------+----------------------------------------------------------------
       cohort |
           1  |          0   (base)
           2  |  -.2142857    .147056    -1.46   0.151    -.5088743    .0803028
           3  |  -.6369048   .1433325    -4.44   0.000    -.9240342   -.3497754
              |
        _cons |   .9285714   .1139091     8.15   0.000     .7003841    1.156759
--------------+----------------------------------------------------------------
```

```
      ACP |
conversati |              cohort
        on |        1          2          3 |     Total
-----------+---------------------------------+----------
         1 |        0          5          4 |         9
           |     0.00      20.83      16.67 |     12.50
-----------+---------------------------------+----------
         2 |       24         19         20 |        63
           |   100.00      79.17      83.33 |     87.50
-----------+---------------------------------+----------
     Total |       24         24         24 |        72
           |   100.00     100.00     100.00 |    100.00

          Pearson chi2(2) =    5.3333   Pr = 0.069

. regress time_dx_acp i.cohort

      Source |       SS           df       MS      Number of obs   =         9
-------------+----------------------------------   F(1, 7)         =      0.84
       Model |  247.338889         1  247.338889   Prob > F        =    0.3886
    Residual |     2049.55         7  292.792857   R-squared       =    0.1077
-------------+----------------------------------   Adj R-squared   =   -0.0198
       Total |  2296.88889         8  287.111111   Root MSE        =    17.111

------------------------------------------------------------------------------
  time_dx_acp |     Coef.   Std. Err.      t    P>|t|     [95% Conf. Interval]
-------------+----------------------------------------------------------------
      cohort |
          2 |         0  (base)
          3 |    -10.55   11.47854    -0.92   0.389    -37.69242    16.59242
             |
       _cons |      62.8   7.652357     8.21   0.000     44.70505    80.89495
------------------------------------------------------------------------------
```