



# HELPING PATIENTS WITH A SERIOUS ILLNESS UNDERSTAND THEIR CONDITION

*Lessons from Oncology*

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## INTRODUCTION

How patients make choices about their medical care relies on accurate understanding of their illness. Patients with a serious illness who have a poor understanding of their disease are more likely to have unrealistic expectations of the goals of treatment and may choose care that is unnecessarily aggressive or not aligned with their wishes. Communication between the patient and their health care team is key to improving their illness-understanding. The Center for Medicare and Medicaid Services (CMS), has developed an Oncology Care Model (OCM). Penn Medicine Lancaster General Health Ann B. Barshinger Cancer Institute (ABBCI) is a pilot site, and our ability to help patients understand their illnesses is assessed through a variety of metrics. This review will discuss illness-understanding in the context of the cancer literature, and then give real world examples from ABBCI on how to improve communication and illness-understanding for patients across the health system.

## ILLNESS-UNDERSTANDING – WHAT IS THE PROBLEM?

Multiple studies have demonstrated that patients with advanced cancer want to have a realistic understanding of their disease in order to prepare for the future while maintaining hope. Those advanced cancer patients who have an appropriate understanding of their illness tend to choose care that is appropriate, and aligned with their overall goals of care. Nevertheless, multiple studies have demonstrated that many patients have inadequate knowledge of their cancer, which can lead to increasingly futile and aggressive care at the end of life, including inappropriate use of chemotherapy, ICU care, and advanced life support.<sup>1-4</sup>

Poor understanding also has a negative impact on receipt of guideline-based care in patients with potentially curable cancers. Breast cancer patients who can correctly identify their stage were 4.45 times more likely to appropriately receive chemotherapy, and 2.76 times more likely to appropriately receive radiation therapy. Though there have been fewer studies of

illness-understanding in potentially curable patients than in those with advanced cancer, studies have demonstrated the same lack of awareness of the stage of disease, and intent of treatment.<sup>3</sup>

## WHAT DOES RESEARCH SHOW?

In 2017 we reported a study of illness-understanding in 208 patients with all stages or types of cancer that were treated at ABBCI within the prior 12 months.<sup>5</sup> Patients self-reported their stage at diagnosis, as well as whether they were free of disease/in remission at the time of the survey. Accurate answers to these questions were garnered retrospectively through chart review, and concordance of answers was evaluated.

Only 51% of patients accurately reported their cancer stage, with concordance ranging from 36.4%-61.5% for patients with stage I-III cancer, and 72% for those with advanced cancer. Thus, concordance was significantly higher among advanced cancer patients than among those being treated with curative intent ( $p=0.0528$ ). Factors associated with greater understanding of stage at diagnosis included higher education ( $p=0.02$ ), income greater than \$60,000 ( $p=0.03$ ), being female ( $p=0.001$ ), and being under the age of 65 ( $p=0.01$ ).<sup>5</sup>

In this same population of patients, accuracy regarding cancer status (remission/free of cancer) was correct 64.4% of the time. Accuracy was similar in patients with potentially curable disease (65.5%), and those with advanced disease (60.5%). Surprisingly, nearly 30% of our patients were unsure about the status of their cancer even when they had no evidence of cancer.<sup>5</sup>

## IMPLICATIONS OF OUR FINDINGS

Our study contributes to the body of literature that illness-understanding is a significant issue. As discussed, in advanced cancer patients this can lead to care that does not align with patient preferences or wishes, particularly at the end of life. In patients with earlier stage disease, poor illness-understanding can

potentially hamper receipt of evidence-based or guideline-based cancer. There can be significant anxiety and psychosocial impact for survivors who do not understand whether their cancer is still active or not. Patients being treated for curative intent may not understand the need for active surveillance or the potential risks of recurrence of their disease. These findings also put into question the informed consent process for accepting treatments such as chemotherapy. Can patients truly consent to treatment without a better understanding of their illness and the goals of the therapies being proposed?

#### WHAT ARE THE BARRIERS TO ILLNESS-UNDERSTANDING?

##### Patient Barriers

Most patients agree that what they want from their physician is a realistic understanding of what to expect from their diagnosis and treatment. They express a desire to be working in a partnership with their physician, feeling supported, and having the ability to ask questions to clarify misconceptions. However, research indicates that preferences on how, when, and why this information should be conveyed to patients are highly variable from patient to patient.<sup>6-11</sup> Patients feel that physicians who are optimistic in their delivery of prognostic information are more trustworthy and compassionate, despite a poor prognosis.<sup>12</sup> In another study, patients who gave physicians the highest ranks for communication skills were the ones most likely to have poor illness-understanding.<sup>13</sup>

Receipt of bad news is often overwhelming, and can impair the patient's ability to process it, leading to poor retention of information. Patients may cope by denying their new diagnosis. Co-morbidities may also prevent patients from accurately processing the data, particularly in an older population.<sup>14,15</sup> Some patients, notwithstanding the information provided by their treatment team, base their understanding and decision-making on personal or religious beliefs.<sup>16</sup> As noted earlier, factors that have been shown to influence a patient's ability to understand the information presented to them include education, primary language, age, income level, and gender.<sup>5</sup> Navigating these murky waters can be difficult for health care teams trying to communicate difficult news, while balancing realism with hope.

##### Health care team barriers

For patients to have accurate illness-understanding, the appropriate information must be conveyed

to them by their health care team. Nonetheless, physicians report varying reasons why this does not occur, even when there is evidence these concerns are mistaken. The reasons include fear that the information will make people depressed or take away hope, or the misconception that involvement of hospice and/or palliative care services will reduce survival.

In the modern era of cancer therapeutics, there is a new challenge of prognostic uncertainty. The treatment of cancer is moving beyond the use of traditional chemotherapy; new classes of drugs such as immunotherapy and targeted therapy offer new chances for prolonged survival, often with much lower toxicity. A few patients may be super responders to these treatments, with no measurable evidence of cancer for years. The introduction of these new agents has led to more options and more sequences of treatments for patients. All these factors can lead to difficulty in formulating an accurate prognosis, and patients who put their hope in these new therapies may delay making critical decisions that express their wishes.<sup>17</sup>

With all this uncertainty, studies have demonstrated that physicians tend to overestimate prognosis, and - when in doubt - err on the side of optimism.<sup>18</sup> This is particularly true for patients they have a longitudinal relationship with and have developed a bond with. Additionally, delivering bad news is emotionally hard, and not something physicians enjoy doing.

The words physicians use, and the time they devote to communication, impacts a patient's understanding. Research has demonstrated that oncologists spend less than 10% of critical visits discussing prognosis.<sup>19</sup> In that same study, physicians also overused medical terminology that a lay person would be unlikely to understand.

#### HOW CAN WE IMPROVE ILLNESS-UNDERSTANDING?

##### What is the impact of communication on illness-understanding?

Communication is a key component in improving the lives of our patients with serious illnesses. Patients who report that appropriate conversations occurred with their physicians had improved quality of life, less aggressive end of life care, and earlier referrals to hospice. This approach was more likely to align with their goals, as those who had these conversations also reported they were less likely to want aggressive, invasive end of life care, reported to be more at peace, and were more likely to know they had a terminal illness. The process of bereavement and adjustment for their

family members was also improved.<sup>20</sup>

In a sentinel palliative oncology study of metastatic lung cancer, patients who were randomized to receive concurrent palliative and oncology care, versus oncology care alone, had better quality of life, mood, and an extension of survival. The palliative care consultations mainly consisted of illness-understanding through communication, patient education, and planning for various medical scenarios. Communication with family members to improve their illness-understanding is also important. Surrogate decision makers do not find false hope acceptable; surrogates who did not have a good understanding of patient's preferences or wishes had more stress, guilt, and doubt over their decision making. Better communication also has the potential for indirect cost savings, due to fewer interventions and less time in the hospital.<sup>21</sup>

#### What is the role of palliative care?

Based on the evidence described here, oncology clinical practice guidelines have recommended integration of interdisciplinary palliative care teams early in the disease course, alongside active treatment for patients with advanced cancer. Consultation should be both in the outpatient and inpatient settings, in order to allow for building of relationships, exploration of illness-understanding, clarification of goals of care, assistance with decision making, and help with coordination of care. In cancer clinical trials, this work was mainly done by consultant palliative care specialists. This may not be realistic in areas with limited resources, or in community settings, and adaptations of this model may be necessary, including training in basic palliative care skills or primary palliative care.

#### Who should be responsible for these conversations?

Good communication is the responsibility of every health care team member who interacts with the patient. However, many patients have multiple providers involved in their care, and expert opinion suggests that one physician should be the communication quarterback who takes the primary responsibility for conversations about goals of care, and then communicates with the rest of the team.<sup>21</sup> Although Palliative Care teams are increasingly sought out for assistance, the palliative care workforce is limited, particularly in resource scarce areas. Thus, it is imperative that all physicians who treat patients with serious illness have the tools to effectively communicate goals of care, and elicit patient preferences. Physicians have varying levels

of comfort in doing so, and it is important they get adequate and continued training and feedback in this area.

#### IMPROVING ILLNESS-UNDERSTANDING AT THE ANN B. BARSHINGER CANCER INSTITUTE

We constantly strive to maximize illness-understanding among our patients with cancer at ABBCI as part of quality care. As noted, we are a pilot site for the CMS Oncology Care Model, and our ability to help patients understand their illness is assessed through a variety of metrics. In this section, I will walk you through examples of how we attempt to reinforce illness-understanding throughout the course of cancer care.

##### Primary Palliative Care

We encourage every oncologist to have an initial conversation with the patient about their prognosis with and without anticancer therapy, as well as about the intent of treatment – not only at diagnosis, but at decision points along the course of care. A nurse navigator or nurse is often present as an additional support to guide understanding and to provide written notes summarizing the discussions at the appointments. For those patients who elect to undergo anticancer treatment, intent of treatment is divided into being either curative or palliative, which is documented for all patients when ordering anticancer therapy through EPIC.

To improve communication, an Institute of Medicine (IOM) care plan is provided for each patient who starts anticancer treatment. This written plan includes diagnosis and stage; whether the intent of treatment is palliative or curative; if the treatment is palliative, what is the average life expectancy with and without treatment; what anticancer therapy is being offered and how its side effects may impact daily life; what other treatment choices may be needed in the course of care; whom to contact for symptoms; and what other support services are being recommended. The IOM care plan is given to the patient, and is reviewed again with the patient by the nurses when the patient presents for anticancer therapy education. A new IOM care plan is generated for the patient and care team each time the patient switches anticancer therapy, and can be found in the synopsis section of EPIC.

Identification and support of high needs patients is an important part of our primary palliative care

model. These patients are identified through daily huddles, worry boards, algorithm-based reports of patients at high risk for readmission, and regular assessments at office visits of pain, nutrition status, depression, and distress. These patients are further supported through nursing intervention, symptom management appointments with advanced practice providers, and oncology support services (social work, financial counseling, nurse navigation, chaplaincy, oncology behavioral health). Each of these assessments and contacts with high needs patients is an opportunity to direct and reinforce illness-understanding.

Advanced care planning is encouraged for all patients regardless of the stage of their cancer at diagnosis. Our certified medical assistants initiate these conversations, and give patients advanced care plans with directions for completion, as well as pamphlets on the importance of advanced care planning, if the patients do not have these documents on file. For the latter patients, the physician conducts a more detailed conversation at an office visit, and details the importance of nominating a health care proxy, as well as executing a living will. Patients who need further help or guidance can be referred to our advanced care planning coordinators.

### Consultant level palliative care

To complement our considerable primary palliative care efforts, we have a robust outpatient, embedded, consultant level, palliative care clinic staffed by two physicians from Palliative Medicine Consultants, as well as an interdisciplinary team of staff from ABBCI oncology support services (e.g. Social Work, Chaplain). This team practices in a dedicated space at the ABBCI designed to be large enough to accommodate family meetings in an inviting atmosphere. Referrals to the team seek management of complex symptoms and psychosocial issues, and goals of care conversations can be made by any medical, radiation, or surgical oncology provider.

Anticancer therapy protocols for advanced lung and pancreatic cancers automatically trigger a consultation, based on literature that shows early intervention by consultant level palliative care in these diseases leads to significantly improved quality of life, illness-understanding, and—in some subsets—survival. We also work closely with the inpatient palliative care team, and currently have a collaboration for early palliative intervention for patients with acute myeloid leukemia.

## Education Modules Available Through CAPC

### Clinical Training skills

- Relief of suffering throughout the disease trajectory
- Pain management curriculum
- Communication skills curriculum
- Symptom management curriculum
- Best practices in dementia care and caregiver support
- Prevention of crises through care of the whole patient
- Management of gaps in care
- IPAL – Palliative care in the ICU and the emergency department

### Operational skills

- Building a community program
- Building a hospital program curriculum
- A leadership support curriculum

Fig. 1. The CAPC curriculum is designed to train health care teams on how to treat and support patients with serious illness.

## RESOURCES TO IMPROVE COMMUNICATION SKILLS AT LANCASTER GENERAL HEALTH

### Center to Advance Palliative Care (CAPC)

Staff members of LG Health have access to a wealth of free training modules, webinars, program development, virtual office hours, and online forums through CAPC. This educational curriculum is not cancer specific and is meant to train health care teams on how to treat and support patients with serious illnesses and their caregivers. (Fig. 1)

Free CME credits are available for each course for physicians, nurses, social workers, case managers, and licensed professional counselors. Additionally, CAPC will be providing American Board of Internal Medicine (ABIM) Maintenance of Certification (MOC) credits for its courses in 2019. (To take advantage of this great opportunity go to [www.capc.org](http://www.capc.org) and register for your free account using your Penn Medicine email address.)

### Serious Illness Conversation Program

The Serious Illness Conversation Program is a structured intervention to aid clinicians in having better and earlier conversations with patients about their goals and wishes, so that clinicians may understand

what is important to each patient, and how that may impact their care. At the center of the program is the Serious Illness Conversation Guide. The guide was developed at Ariadne Labs at Harvard University, and addresses key patient-centered issues, including:

1. The patient's understanding of their illness,
2. Their preferences for information,
3. Sharing their prognosis,
4. Assessing their goals, fears, worries, strengths, abilities, tradeoffs, and involvement of family,
5. Communicating the health care team's recommendations.

The guide was tested in clinical trials and found to produce better quality conversations that happened earlier in the course of care. Patients who participated in the interventions reported less anxiety and depression than the control group. Currently, our Penn Medicine partners have disseminated this important

work through the cancer service line.

At LG Health we will be initiating the Serious Illness Conversation Program with our cancer patients starting July 2019, but this program can be used for any patient with a serious illness. To learn more, visit: <https://www.ariadnelabs.org/areas-of-work/serious-illness-care/>

## CONCLUSION

For patients to make informed choices about their health care, it is crucial that they understand their illness. Although there are various barriers, health care providers can optimize their role in illness-understanding by continually improving their own communication skills. Additionally, illness-understanding can be enhanced by having clinic processes that support ongoing sharing of information with patients and caregivers all along the course of their care.

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