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Creating A Core Competency: Shared Decision-Making and Financial Navigation

"Shared Decision Making for Financial Advocates Summit" Pre-Reading

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Background

The cost associated with cancer care is a topic that has garnered widespread attention among policymakers, providers, and patients and their families. The United States leads the world in costs associated with cancer care and economists warn that healthcare costs, of which cancer is a major contributor, threaten our nation's ability to remain competitive globally. The data is stark in its details. It is estimated that 28 million patients, 75 percent of whom have health insurance, have exhausted their savings because of medical debt and are facing bankruptcy.[1] Twenty-one million have incurred large credit card debt and will forego necessities because of medical bills.[1]

For patients, the burden of cancer stretches beyond the physical rigors of treatment. The "financial toxicity" created by the cost of cancer care is associated with not only a greater likelihood of declaring bankruptcy (2.65 times greater) but also among those who have declared bankruptcy a 79% greater mortality risk.[2] In addition, half of elderly cancer patients are underinsured.[3] Cancer financial toxicity has been associated with greater patient anxiety, worse quality of life, treatment non-adherence, and higher mortality.[4]

National oncology leaders have issued a call to action and have proposed interventions initiated by the oncology team. Specific recommendations include:

1) Oncologists should focus on the value of care delivered and discourage the use of interventions of little benefit but high cost
2) Oncologists should initiate the "costs" conversation and goals of care at the outset of treatment
3) Physicians or designated staff member must be prepared to engage in the costs of care conversation with patients and families
4) Patient interventions must focus on improving patients' cost-related health literacy knowledge.[3]

Moreover, the National Academy of Medicine (NAM, formerly, named the Institute of Medicine) has called for shared decision-making in cancer care. To achieve this, the NAM 2013 report, "Delivering High Quality Cancer Care: Charting a New Course for a System in Crisis," recommends that "the cancer care team should provide patients and their families with understandable information on cancer prognosis, treatment benefits and harms, palliative care, psychosocial support, and estimates of the total and out-of-pocket costs of cancer care [emphasis added].[4]

Shared decision-making is being consistently promoted as an essential component of patient-centered care and the therapeutic alliance.

Scholars have been arguing for cost transparency as part of patient engagement and informed patient choice for years. Harlan Krumholtz, MD, SM, of the Yale School of Medicine, has proposed a sweeping reform of the informed consent process to include costs associated with treatment and the experience of the team, e.g., number of cases treated.[5]

Simply stated, costs affect choice. The ethical imperative to have an engaged and truly informed patient through shared decision-making and cost information is nowhere greater than in cancer treatment.

The American Society of Clinical Oncology (ASCO) has promulgated a patient physician cost communication guidance statement, central to which is the requirement for an open dialogue in which the patient is:

- **asked** about the potential financial impact,
- **advised** about what treatment option is most valuable, and
- **referred** to a patient financial assistance program if the treatment would place the patient at risk for financial toxicity.[6]

However, barriers to cost transparency are real and include access to accurate cost information that can be meaningfully shared with the patient. As such, access to an accurate "costs of care" database that can generate by CPT code and zip code, average cost information is a prerequisite. Training for providers and financial advocates is also imperative in order to facilitate cost conversations and informed shared decision-making.

Development of a financial health literacy module for patients and families would provide a practical foundation for discussion of cost of care. This resource would support patients and families in reviewing details of their insurance coverage with a cancer program's financial advocate. Then, over the cancer care trajectory, the financial advocate then becomes a single point of contact, who can assist the patient should coverage change and/or help identify additional resources to lessen the economic burden of cancer such as applicable patient assistance programs or foundations.

What is being proposed is the creation of a core competency training of financial navigators as a means to engage patients at the outset with goals of care and cost information to support the shared decision-making process.

Core Elements of Financial Navigation Programs

Financial navigation programs vary across cancer centers, based on a variety of key factors including organization capacity, patient volume, available resources, and the extent to which the medical team are already involved in patient engagement and shared decision-making. However, tantamount to the success of any financial navigation or advocacy program is a clearly articulated vision from organizational leadership to fully understand and address the negative impact of the financial cost of care on all aspects of cancer patients' access and utilization of services and their subsequent quality of life, morbidity, and mortality.

Cost of care has very real consequences for patient and their families. The financial impact can result in challenges paying for groceries or utility bills and difficulty paying the mortgage or rent, which can often lead to legal challenges such as filing bankruptcy. Costs of cancer services and care spans the continuum from accessing cancer screenings through active treatment and post-treatment survivorship. Assessing patient challenges and needs along the care trajectory is critically important, particularly for traditionally underserved populations that are often vulnerable to policies that essentially shape their options within the context of cost and that can limit conversations around finances and shared decision-making. Creating and sustaining an effective Financial Navigation or Advocacy Program requires key institutional and programmatic elements including:

I. Proactively identify and evaluate how to maximize the patient's health insurance benefits.
II. Proactively reduce economic barriers to care by having working knowledge of available patient assistance programs, financial advocacy tools, and resources.

III. Accurately explain insurance coverage and assistance options and skillfully communicate with patients and their caregivers focusing on issues of cost of care, patient assistance support, and additional resources.
IV. Manage, track, and report on all financial advocacy and patient access services interactions.
V. Ensure that providers and cancer program staff are aware of ongoing policy requirements from payers for coverage of services.
VI. Help mitigate institutional financial toxicity.

Financial Navigation Programs whether freestanding or embedded in a wider navigation program require a culture shift within the cancer team, infrastructure to support shared decision making across the cancer continuum, and development of an algorithm that takes into consideration the costs and options that can impact access to cancer care services along the disease trajectory.

Culture Shift

Green Bay Oncology reports several culture shifts over the past five to ten years.

As insurance costs started to rise, along with the requirement for patients to have health insurance, the practice has experienced a shift from seeing more uninsured patients to seeing more who are underinsured. Although patients now have insurance, they can't afford their out-of-pocket costs. In 2014 Green Bay started meeting with patients proactively to discuss their out- of-pocket costs and what they would be financially responsible for based on current review of their benefits. For patients who had additional daily living needs costs that could not help with, the practice brings their social workers into the discussion. In turn, social workers reach out to the financial advocates if patients express concerns that these staff can assist with.

Patients today seem more willing to talk with a designated financial representative than several years ago. Green Bay has also included financial concerns as part of the patient's distress screening so that patients are aware from the start that the practice acknowledges this is an issue, which opens the door for discussion of financial concerns as part of their routine care.

Organizational Infrastructure

Green Bay Oncology has a financial advocacy team that is embedded in the medical and radiation oncology clinics so that they are available to talk with patients any time throughout the day. One financial advocacy team member reviews insurance coverage allowing the remaining team members to discuss current and remaining out-of-pocket expenses with patients/families, perform all authorizations as required by payers, and enroll patients in foundations or patient assistance programs as needed. This team provides a single point of contact for patients and families for financial issues from authorizations through appealing any potential denials. In addition, the Green Bay financial advocacy team has a single contact within the Revenue Cycle Department who is responsible for all foundation billing. This allows for smooth billing to foundations and quicker payment. If patients have concerns about any medical bills they bring these to the financial team who will work with other providers or clinics to look for any additional assistance that may be available.

Longitudinal Navigation

The Duke Cancer Institute (DCI) has a robust Longitudinal Patient Navigation model that spans from Community-Facing Navigators to treatment and survivorship navigators housed within the cancer center. Implemented as a health equity model, the DCI program improves access and utilization of cancer health services, with a heightened focus on underserved populations, by eliminating barriers to care and connecting community members and patients to relevant services and resources. Community Navigators educate the community in a variety of strategic settings, identify those who need cancer screening, and remove the psychosocial and financial barriers that prohibit access to cancer services. Community Navigators engage patients in a full assessment, and specifically incorporate a dialogue around cost barriers based on a locally defined financial algorithm. This process both secures payment for cancer screenings while proactively eliminating financial barriers to cancer treatment, if diagnosed.

The Community- Facing Navigators provide a warm-hand off to Patient Navigators within the Duke Cancer Support Program, which is housed within the cancer center. Patient Navigators then partner with patients throughout their cancer journey to identify and address new and ongoing psychosocial and financial barriers that compromise seamless access and utilization of cancer care. Throughout this process patients and their navigators work together to prioritize patients' needs and make choices based on a wide array of comprehensive services in place to alleviate psychosocial and financial stressors, such as one-on-one financial and legal clinics and other resources available for patients and their families within the cancer center.

The Longitudinal Patient Navigation Matrix aims to keep the patient connected throughout the cancer care continuum and to eliminate of barriers to care, particularly those associated with the financial burden at the start of the cancer journey. The navigators in this model are diverse in their training, disciplines, and roles. Navigators include, but are not limited to, lay community, nurses, social workers, clinic staff, and public health educators. A transdisciplinary team, which includes the patient and the care team, coupled with comprehensive services to address barriers to care has the opportunity to enrich and enhance support and the perspectives needed to address the complexity of cancer diagnosis and treatment, and particularly the financial burden associated with the disease from screening through active treatment and post-treatment survivorship.

Pilot Programs – Lessons Learned

Munson Medical Center in Traverse City, Michigan, began its financial navigation program in 2013. At that time, the cancer program consisted of three separate private physician offices, an outpatient infusion center, and an outpatient radiation program. The program was transitioned to a hospital-based system when they moved into the cancer center. The program has two hospital-based oncology financial navigators equaling one FTE position. The financial navigators received education on insurance optimization and then began their program, which included an insurance review followed by a meeting with those patients we determined to be underinsured or uninsured. Initially, the program's main goals were insurance optimization and finding assistance for patients. During its first year, the program was able to assist enough patients to justify 2 FTEs. The financial advocates would travel to the patient, meeting with them at the physician offices or in the infusion and radiation areas. During this time, the financial navigators built trust with providers and the clinical team.

Three years ago, the cancer program services moved under one roof forming the Community Cancer Center. The financial navigation program, which was already off to a great start, began to really grow. This was due, in part, to the accessibility of the financial navigation team for both patients and staff, and also to the financial navigation team's collaboration with the care providers, social work, and nurse navigators. In Munson Cancer Center's experience, it is important for the financial navigation team to report directly to the cancer service line, as that allows the program to be more patient-centered.

Conclusion

Shared Decision Making in the Context of Clinical Care

The term shared decision making first arose out of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1982 publication, "Making Health Care Decisions: A Report on the Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship."[7] The Commission members, representing the fields of law, medicine and ethics, gathered to advise how to improve patient physician communication in light of the rapid change in the common law recognizing the legal principle of informed consent. The members decried the practice of a "ritualistic signature on a written form" and suggested that there be a new model in which the physician shares relevant information about the risks, benefits, and alternatives to the proposed treatment, and the patient shares their values and preferences so that together patient and physician decide what is best for the patient.

The limitations of a written informed consent form are obvious. Too often the patient does not understand the risks and there has been no meaningful communication between provider and patient. The one-dimensional push of information as represented by the "form" suffers in numerous aspects of communication and pales in comparison with the bidirectional exchange of information which is heart of shared decision making.

Recently the National Quality Forum issued a national call for shared decision making to become part of standard clinical practice. Additionally, the Council of Medical Specialty Societies representing over 700,000 physicians has endorsed this call to action. In the NQF action plan[8] shared decision making is clearly defined:

> "Shared decision making (SDM) is a process of communication in which clinicians and patients work together to make optimal healthcare decisions that align with what matters most to patients. SDM requires three components:
>
> - Clear, accurate, and unbiased medical evidence about reasonable alternatives—including no medical intervention—and the risks and benefits of each;
>
> - Clinician expertise in communicating and tailoring that evidence for individual patients; and
>
> - Patient values, goals, informed preferences, and concerns, which may include treatment burdens."

Inherent in the shared decision-making process is the potential use of patient decision aids. These are tools that facilitate patient engagement and assist patients in assessing their values. As defined by the National Quality Forum:[8]

"Patient decision aids are tools designed to help people better participate in healthcare decision making. These resources provide information on the risks, benefits, and alternatives as well as burdens of options and help patients clarify and communicate their personal values on different features of the options. Patient decision aids do not advise people to choose one option over another, nor do they replace clinician consultation. Instead, patient decisions aids prepare patients to make informed decisions, together with their clinicians, that align with their values, goals, and preferences."

Shared decision-making is most commonly recognized in clinical practice where a patient has more than one clinical option. For example, in early stage breast cancer a woman has two choices-lumpectomy or mastectomy.

The benefits of shared decision-making are well established. The most recent Cochrane review of 115 randomized control trials update highlights considerable evidence of impact:

> In 115 trials addressing 23 different screening or treatment decisions, with the use of quality decision aids has led to:
>
> - Greater knowledge
> - More accurate risk perceptions
> - Greater comfort with decisions
> - Greater participation in decision making
> - Fewer people remaining undecided
> - Fewer patients choosing major surgery

The Cochrane editors go on to state:

> "Compared to usual care across a wide variety of decision contexts, people exposed to decision aids feel more knowledgeable, better informed, and clearer about their values, and they probably have a more active role in decision making and more accurate risk perceptions. There is growing evidence that decision aids may improve values-congruent choices. There are no adverse effects on health outcomes or satisfaction. New for this update is evidence indicating improved knowledge and accurate risk perceptions when decision aids are used either within or in preparation for the consultation."[9]

Many legal commentators have called for shared decision-making to become the gold standard for informed consent given the consistent and positive results on patient knowledge and the strengthening of the therapeutic alliance. In one large patient survey the results of shared decision-making with the use of quality decision aids prompted the organization to make the use of shared decision-making a fundamental tenet of patient care. The Group Health survey of over 2,200 patients underscores the effect that shared decision-making with the use of a quality decision aid has on the patient experience of care (see Exhibit 1, below).

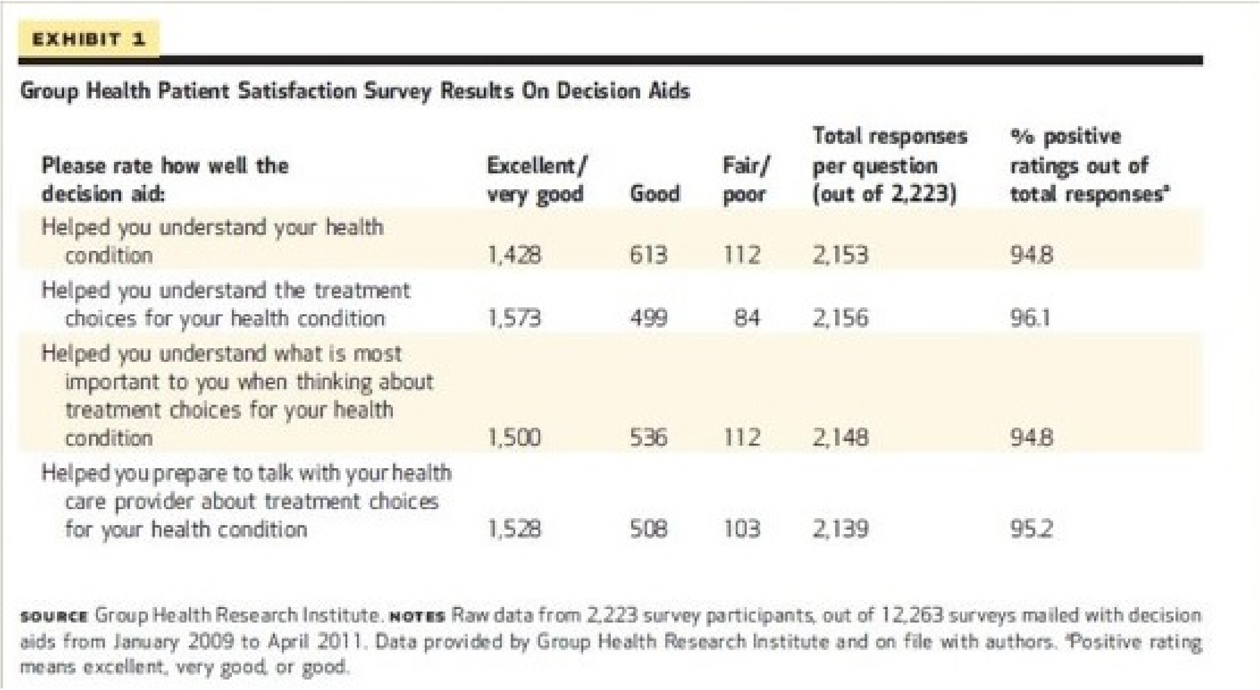

EXHIBIT 1

Group Health Patient Satisfaction Survey Results On Decision Aids

Please rate how well the decision aid:	Excellent/ very good	Good	Fair/ poor	Total responses per question (out of 2,223)	% positive ratings out of total responses[a]
Helped you understand your health condition	1,428	613	112	2,153	94.8
Helped you understand the treatment choices for your health condition	1,573	499	84	2,156	96.1
Helped you understand what is most important to you when thinking about treatment choices for your health condition	1,500	536	112	2,148	94.8
Helped you prepare to talk with your health care provider about treatment choices for your health condition	1,528	508	103	2,139	95.2

SOURCE Group Health Research Institute. **NOTES** Raw data from 2,223 survey participants, out of 12,263 surveys mailed with decision aids from January 2009 to April 2011. Data provided by Group Health Research Institute and on file with authors. [a]Positive rating means excellent, very good, or good.

Melding Traditional Shared Decision-Making Concepts with the Role of Financial Navigator

Costs and their associated impact on treatment choice have been debated as a necessary adjunct to informed consent. Harlan Krumholtz, MD, SM, from Yale School of Medicine, has argued that inherent in the informed consent communication is access to cost information. In many cancer programs today, financial navigators are the team member who helps the patient access and understand information on the cost of care. To support informed shared decision-making, financial navigators can work with the cancer care team to assist patients with an understanding of their out-of-pocket costs and their insurance reimbursement. This will allow patients to understand the financial impact that the treatment proposed will have on their finances. Resources such as FAIR Health [www.fairhealth.org], which offer providers and patients information on the average costs associated by CPT code and zip code, can be consulted. With proper training financial navigators can facilitate the shared decision-making process so that patients are engaged, given meaningful information about costs of care, and assisted in navigating the insurance pathways so that financial toxicity is minimized.

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The ACCC Financial Advocacy Network is the leader in providing professional development training, tools, and resources that will empower providers to proactively integrate financial health into the cancer care continuum and help patients gain access to high quality care for a better quality of life.

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