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ACCC Financial Advocacy Network Shared Decision Making Summit Executive Summary

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Hogan Lovells US LLP
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Introduction

Pam Rattananont Ferris, MPH, former ACCC Director of Development, introduced the meeting by welcoming everyone in attendance and thanking them for participating. Ms. Ferris reviewed the objectives of the meeting:

- Formalize a definition of shared decision making within financial advocacy.
- Gain a better understanding of how shared decision making can be improved within financial advocacy.
- Identify recommendations for improved shared decision making within financial advocacy.

Shared Decision Making for Financial Advocates

Mr. Moulton began his presentation by asking attendees another central question for the summit: How do you include the issue of cost in conversations with patients? Mr. Moulton then highlighted knowledge gaps between patient and provider. Most patients have differing opinions on their prognosis than their provider, and half of patients do not know the stage of their own cancer. Statistics like these demonstrate a lack of informed consent—an ethical obligation enforced under law that requires patients to be given reasonable, objective information about their condition and treatment options. Standards for informed consent vary from state to state; this information could either reflect what an average patient would want to know, what an average qualified physician would want to know, or a combination of both.

Mr. Moulton argues that shared decision making (SDM) must occur to achieve true informed consent. Shared decision making is defined as 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 is crucial to patient safety, satisfaction, and engagement, and can be seen as risk mitigation for providers. Three components are required:

- Clear, accurate, unbiased medical evidence about reasonable treatment alternatives (including no treatment) and their risks and benefits
- Clinician expertise in communicating that evidence to patients
- Incorporation of patient values, goals, preferences, and concerns, which may include treatment burdens

To assist in SDM, providers can utilize patient decision aids (PtDAs), which provide information on risks, benefits, alternatives, and the burdens of treatment and assist patients in communicating their personal values to providers. They do not replace consultations, but instead inform SDM by taking patient preferences and values fully into account. In several studies, using PtDAs has been proven to improve SDM; in 130 trials, PtDAs led to greater patient knowledge, greater comfort with decisions, greater participation in decision making, and more accurate patient perception of risk. The Centers for Medicare & Medicaid Services (CMS) is beginning to require the use of certified PtDAs, and payment may soon be linked to their use. The National Quality Forum's (NQF's) National Quality Partners Playbook: Shared Decision-Making in HealthCare includes PtDAs that can be used to educate patients.

Mr. Moulton closed by saying that the use of PtDAs to strengthen shared decision making would be a useful step for patient financial advocates in addressing financial toxicity and the financial burden of cancer. Shared decision making should require patient knowledge of insurance coverage, out-of-pocket (OOP) cost, and financial toxicity; informed consent cannot be informed without an awareness of the financial implications of treatment.

The Patient Perspective on Shared Decision Making

Dr. Balch next presented on a survey conducted by the Patient Advocate Foundation (PAF) in May 2018, in which 1,371 patients (568 cancer patients) who received PAF services in 2017 were asked about the financial burden of their treatment. The results of the survey showed that 70% of cancer patients experienced financial hardship due to the cost of their care, and 42% of cancer patients reported that it was severe. The greatest source of this strain was due to insurance-related cost. The cost of treatment affected treatment choice, treatment adherence, and the ability to afford necessities such as food and rent.

While most patients survey discussed treatment options and decisions with their doctors, only 30% discussed the cost associated with treatment options, indicating a gap in shared decision making. More cancer patients (47%) obtained information on cost from insurance companies rather than doctors (32%) or patient navigators (24%). Patients expressed an overwhelming desire to know more about the cost of all aspects of their treatment, including office visits, prescription drugs, and lab testing; in previous years, patient sentiments about discussing cost were very different, citing privacy and comfortability. Patients wanted to know what resources were available for reducing cost, what questions to ask providers, access to information about care-associated cost, and, most importantly, confidence that bringing up the cost of care during treatment discussions would not impact access to the best care possible.

The Clinic Perspective on Shared Decision Making

Lori Schneider, Business Office Manager, Green Bay Oncology, and member of the ACCC Financial Advocacy Network Advisory Committee, offered the perspective of a cancer care clinic on shared decision making. Historically in the patient–provider decision making process, patients received no advanced information on OOP costs, often leading to their inability to make payments. As a result, in many instances the supervising physician would “write off” their debt, removing it from their account. This resulted in a significant loss for the clinic. In 2006, Green Bay Oncology introduced the financial counselor position to review insurance coverage terminology and the drug compendia for approved coverage, develop oral medication and specialty pharmacy processes, and work with manufacturers to obtain free medication for uninsured patients. Later, as OOP costs began to rise and insurance company preauthorization’s began to increase, the financial counselor’s role expanded to include insurance coverage verification, checking coverage for high OOP costs, assisting under- and uninsured patients in finding insurance, enrolling patients in foundations, and working with social workers to address non-medical expenses.

At different clinics, the level to which providers discuss cost with patients varies. At Green Bay Oncology, distress screenings include financial questions, and if there are coverage issues, patients work with providers and financial counselors to achieve SDM. Ms. Schneider says that physicians have a hard time keeping up with information and updates regarding cost, and patients often don’t know when they want to receive information about cost—during initial consult or at a follow-up appointment. Clinics need greater training for financial advocates and better PtDAs for different patient learning styles (visuals, teach-back, diagrams, articles, etc.). Green Bay Oncology has a continuous process improvement program that has resulted in proactive meetings with patients to discuss insurance, designated teams for all medical financial concerns, and a hospital foundation for oral specialty medications. These financial counselors allow providers to focus on medical care, reduce patient anxiety and financial toxicity, increase patient satisfaction and access to foundation funding, and prevent the financial loss of “write off” dollars for the cancer program.

Effective Navigation Programs and Key Elements of Success

Nadine Barrett, PhD, MA, MS, Director of the Office of Health Equity and Disparities at Duke Cancer Institute, shared a presentation on how her program approaches financial toxicity from a socioeconomic perspective to address disparate health outcomes for underserved populations. According to observed data, underrepresented communities fare worse in most outcomes, and it is important that we provide those groups with the appropriate resources, models, and programs to achieve health equity. To understand the needs and challenges to these populations, Duke Cancer Institute (DCI) established the Diverse Community Advisory Council to join in intimate collaboration with their community to better understand their needs and challenges through focus groups, town halls, listening sessions, and surveys among other methods; this process is ongoing.

From there, DCI established the Office of Health Equities and Disparities (OHED), which developed a longitudinal model and algorithm to guide patients around barriers to healthcare by identifying which patients would require greater information about cost of care. With their Community Facing Navigation Program, DCI finds participants in the community, assesses their needs and barriers, takes a financial assessment, performs a cancer screening, and refers them for follow-up. To overcome barriers to care, OHED can work with employers to adjust work schedules, provide childcare services to those who need it, and make extensive use of community resources like faith-based transportation programs to facilitate the screening process. OHED is formally training all patient-facing staff in navigation so that they know who to refer patients to at what times. In two years, OHED has educated more than 5,000 individuals in the community on cancer risk, symptoms, screenings, and research; screened more than 1,500 people, more than one-third of whom are undocumented and more than half of whom are uninsured; and provided necessary follow-up care for 52 of those screened patients through a hand-off to DCI Support Services, which has a group of diversely trained navigators to identify and address patient needs and continuously assess for distress and financial toxicity. With the use of their algorithm, DCI's model is scalable up or down depending on patient population size.

Panel Discussion

Dr. Barrett, Ms. Schneider, and Clara Lambert, BBA, OPN-CG, Oncology Financial Advocate at the Advocate Good Samaritan Bhorade Cancer Center and ACCC Financial Advocacy Network Advisory Committee Chair, next participated in a panel discussion on effective patient navigation programs. Dr. Barrett elaborated on the success of OHED, saying that provider buy-in was necessary, as was having the deputy director of DCI as a champion. Learning sessions and very strong community relationships are also critical to the success of the program at Duke. Dr. Barrett elaborated on OHED's algorithm, saying that it breaks down into regions and then further subdivides. It also maps out transportation and community resources; the longitudinal patient navigation matrix will be coming out soon in a publication. Dr. Barrett stressed the need to be proactive in financial assessment.

Ms. Lambert relayed her experience establishing herself as a familiar face to physicians at tumor boards and in their offices in order to help bring forward the importance of financial advocacy services. Ms. Lambert said that one of the biggest challenges to successful patient financial navigation is a lack of co-pay assistance and foundation funding; the amount previously available has made an increase in demand difficult to sustain. Ms. Schneider added that factors that help support a successful financial advocacy program include designing a replicable program/model and including patient/family input in developing education for financial navigators. As a financial navigator, Ms. Lambert shared that her main goal is to reduce the cost of care for her patients, with the

additional goal of ensuring the program is able to break even, which helps support administrative buy-in. All three panelists agreed that to facilitate SDM, financial navigators would need to intervene at many points across the care continuum, including pre-diagnosis, during tumor boards, finding funding for medication, and during post-treatment survivorship. DCI is piloting SDM programs at a breast cancer clinic with their survivorship team.

Understanding and Navigating Financial Distress

Teresa Hagan Thomas, PhD, RN, Assistant Professor at the University of Pittsburgh School of Nursing, next presented literature/research on financial toxicity. Financial toxicity is defined as a combination of objective burden and subjective distress; while 28–48% of cancer patients reported monetary distress, 16%–73% reported objective or subjective financial toxicity. Patients experiencing financial toxicity suffer higher OOP costs, asset depletion, loss of productivity, reduced insurance options, and reduced funding for food, clothing, and leisure activities. As a result, they experience distress, are less likely to adhere to treatment, have lower quality of life and health, and have decreased survival/increased (risk of) mortality. About half of patients want to discuss treatment-related OOP costs with doctors; however, only 22% actually do with a median duration of 33 seconds, and 38% of those conversations mention cost-reducing strategies. Patients also don't want personal or societal cost to influence their treatment, although low-income patients are more likely to avoid expensive treatment. However, patients believe that discussing cost will decrease the quality of their care, waste provider time, and be potentially embarrassing.

When it comes to measuring distress, there are a variety of tools, including the financial toxicity grading scale, the Comprehensive Score for Financial Toxicity (COST), and National Comprehensive Cancer Network (NCCN) Distress Thermometer, but no standard tool is applied across all cancer programs to assess for financial distress. Additionally, few studies exist on alleviating financial toxicity aside from unreliable retrospective analyses. To fight financial toxicity, a number of actions should be taken, Dr. Hagan stated, including the validation of a screening tool, defining the trajectory of financial toxicity for unique patient populations, and identifying and testing intervention targets and timing. Policy change should also be effected, including increased drug cost transparency, oral drug parity laws, CMS negotiation of drug pricing, and the expansion of the Medicaid Drug Rebate Program, among others, Dr. Hagan noted.

Preliminary Financial Distress Screening Survey Results

Abra Kelson, MSW, LSWA-IC, Social Worker Supervisor at Northwest Medical Specialties and ACCC Financial Advocacy Network Advisory Committee Member, next presented the results of an ongoing financial distress screening survey conducted by the ACCC Financial Advocacy Network. Sixty-eight respondents answered seven questions about their cancer program's financial distress screening methods. Of survey participants, most report having 1 to 2 FTE/full time financial advocates or equivalent. Half of respondents indicated that their program uses the NCCN Distress Thermometer to screen for financial distress, while the rest use a variety of tools; implementation of these tools is equally varied. Data collection is ongoing and results will be presented next year.

Panel Discussion

Dr. Thomas and Ms. Kelson joined in a panel discussion with Virginia Vaitones, MSW, OSW-CE, FAOSW, ACCC Past President and retired Oncology Social Worker, and Nicole Taglione, Oncology Financial Navigator at the Saint Agnes Cancer Institute. The panelists discussed a lack of representation in financial toxicity research for pediatric/AYA cancer patients and 25- to 35-year-old patients. When asked if a conversation about financial

distress should occur with every patient, panelists offered varied options. Dr. Thomas stated that each patient should be assessed/evaluated and screened individually for risk, while Ms. Taglione believes that finances should be discussed with all patients because patients may not realize the impact of cancer care costs. Ms. Vaitones related that in her experience patients did not want to discuss cost at every visit, and Dr. Thomas stated that patients learn how to quickly fill forms with some general responses so that they won't have to answer the same questions repeatedly, or in additional screening surveys. All panelists agreed that enabling patients to discuss the cost of care openly with their providers was critical to addressing financial toxicity. Panelists also discussed how screening tests like the NCCN Distress Thermometer are distributed and incorporated into electronic health records (EHRs). Older patients might struggle with the new technology, but when phased in correctly, the transition from pen and paper to tablets and iPads can help with more routine financial distress screening.

Navigating Medicare and Medicaid

Dan Sherman, MA, LPC, Financial Navigator Consultant at The NaVectis Group, gave a presentation on the difficulties that financial navigators face in navigating the Medicare and Medicaid landscape. Patient advocates need to be able to sit down with patients and explain Medicare plans to them, as diverse as they are, in order to ensure that their consent to treatment is properly informed. Given the complexity of healthcare insurance landscape, nuances of individual coverage policies, and the potential economic impact for patients and their families, there is a pressing need for consumers to have access to financial advocates with the skill and knowledge to help demystify plan coverage and assist patients in optimizing their insurance.

Mr. Sherman outlined the various Medicare plans as well as difficult insurance scenarios patients might face during their care. He suggested focusing attention on a proactive navigation process for Medicare and Medicaid so that patients wouldn't have to deal with the stress of losing coverage or changing coverage without assistance. By targeting financial distress screening on specific patient populations (e.g., Medicare-only patients, patients new to Medicare, Medicare beneficiaries without Part D), navigators can ensure greater equity among disadvantaged populations. He also shared his preferred method for obtaining assistance for patients, including Medicaid as a first option, assessing Low-Income Subsidy qualification, and assessing the affordability of supplemental policies.

In an open discussion, all summit attendees agreed that there should be a certification process for healthcare providers to discuss public insurance options with patients. Patients can't be expected to become experts, and there should be people within cancer programs that can provide expert assistance to those patients. Some participants noted that their organization discourages them from providing insurance advice. Mr. Sherman recommends certification in financial advocacy, which would help avoid such conflicts of interest, and even holding open houses to demonstrate the value of the financial advocacy services. Mr. Sherman said that in order to become an expert in this field, above all else it requires passion. Patients must trust their navigators completely, and there are emotional implications when discussing insurance plans. Dr. Balch shared that foundations are unable to triage aid applicants based on suitability for need, so if programs could be proactive about suggesting insurance coverage and using foundation assistance as a last resort, it would go a long way in helping more patients in need. Patients also apply for and receive their foundation support much quicker, which has resulted in decreased availability. Insurance optimization can be a scary subject to broach, but it can be used to motivate patients and get them the help they need.

Integrating Telehealth Practices into Financial Advocacy

James McElligott, MD, MSCR, Executive Medical Director of Telehealth at the Medical University of South Carolina, shared a presentation on the incorporation of telehealth into health systems. Telehealth is about human contact, like a virtual house call. More than 70% of large employers offer telemedicine, which encompasses the practices of medicine, health education, public health interventions, and health administration at a distance. Dr. McElligott highlighted the Medical University of South Carolina's telehealth programs, including school-based telemedicine, telestroke consults, tele-ICU, remote monitoring of diabetes patients, and examinations conducted via smartphone. Such programs have increased patient volume and efficiency, decreased patient cost and unnecessary hospital visits, and offered greater flexibility for patients and providers to have conversations about care. The telehealth network has received more than \$100 million in state funding since 2012–2013, making it a significant value addition for the health system. Telehealth also offers the possibility for reimbursement innovation due to its unique nature. As telehealth will only grow in prevalence and importance, it is important to harness it for the purpose of influencing shared decision making.

Next, Mirna Becevic, PhD, MHA, Assistant Research Professor at the University of Missouri, shared how Missouri Telehealth Network has implemented telehealth, including the development of Project ECHO (Extension for Community Healthcare Outcomes). Telehealth alleviates many issues with modern healthcare, including clinician shortages and maldistribution, lack access, travel concerns, late diagnosis, insufficient clinical education, and a lack of local economic development. Project ECHO was put together as an education program using videoconferencing to give community practitioners access to specialist expertise, therefore improving the ability of local practitioners to treat patients where they live. ECHOs exist for a range of conditions, including asthma, chronic pain, endocrinology, hepatitis C, and opioid use disorder, among others. Each ECHO also includes a health literacy expert to analyze provider communication and share useful materials for patient communication. Through survey results, these ECHOs are shown to have increased population health literacy and patient ability to understand care instruction. By utilizing available technology, cancer programs can bridge access and education gaps, and including health and financial literacy components in that education can combat financial toxicity and improve shared decision making.

Panel Discussion

Dr. McElligott and Dr. Becevic cautioned that telehealth is not designed to replace in-person visits, which are the standard of care; it is always better to meet in person, but with telehealth programs you can maintain more accurate and frequent contact with patients, including those at risk for financial toxicity. One common barrier to telehealth implementation is a lack of buy-in due to unfamiliarity or unwillingness to learn about new technology; high demand in rural areas may force a change, and a younger workforce more comfortable with technology can increase telehealth presence. Regulatory barriers also exist, as most telehealth networks can't provide access across state lines. However, many hospitals are being credentialed to provide telehealth, and partnering with a larger organization can allow for credentialing by proxy, potentially across state lines.

Conclusion

Mr. Moulton concluded the summit by discussing some common barriers to shared decision making for physicians (lack of knowledge about cost and associated issues, the potential for cost to impact treatment options) and patients (embarrassment, a lack of prior knowledge, respect for a provider's time). Through today's discussion, a number of methods to improve shared decision making were discussed, including the use of non-clinician support staff to supplement a clinician's medical perspective; explaining treatment options fully including associated costs; and standardizing financial distress screening tools across cancer programs and practices.



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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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