

Shared Decision-Making in Health Care

Fuqua School of Business
Duke University

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Health Sector Advisory Council & Collaborative on Healthcare
for Aging Populations and Advanced Illnesses (HSAC/CHAPI)

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Thursday, November 14th, 2013: Collaborative on Healthcare for Aging Population and Advanced Illnesses (CHAPI) Meeting

Framework for ‘shared decision-making’ and current research perspectives

Presenter: **Jeff Belkora**, Associate Professor of Surgery and Health Policy at the University of California San Francisco

Key Points

- 5S model for health care decision-making;
- Importance of patients utilizing multiple channels to receive and process information regarding health care options;
- Components of ‘meeting hygiene’ to support better SDM in a clinical setting.

As a systems engineer Dr. Belkora has worked to create a ‘theory of action’ around decision-making in healthcare. He has called this the S5 Model. The 5 Ss include the following components, each a component that influences and informs decisions in healthcare:

- 1) Somatic (including instinct, reflexes, ‘gut feelings’)
- 2) Social (including input from peers, and the built environment)
- 3) Spiritual (including looking to a Higher Power for guidance)
- 4) Soulful (including looking introspectively at one’s identity to guide choices)
- 5) Scientifically (including weighing risks and benefits)

He suggested that in making complex decisions it is important for people not only to handle information internally, through activities like reading information and thinking, but also to externalize the reflection process by talking with others and writing. Dr. Belkora developed the SCOPED checklist, which encourages thinking, talking, reading and writing through decision-making. Dr. Belkora also briefly introduced the FAST method, which encourages critical reflection for patients before, during, and after appointments.

Dr. Belkora then discussed elements of meeting hygiene that can support shared decision-making (SDM) in doctor/patient interactions. These can include:

- Providing multiple channels of information through which information is shared with, and received by, patients and loved ones (ie – notes, recordings, etc);
- Utilizing health coaches to help patients generate a list of questions for doctors before appointments;
- Utilizing health coaches to attend doctor appoints with patients and take notes, and then share information from the appointment with patients in patient friendly, plain language.

Clinical Research Study on Care at the End of Life Shared Decision-Making

Presenter: **Rachelle Bernacki**, Direct of Quality Initiatives in the Department of Psychosocial Oncology and Palliative Care, Dana Farber Cancer Institute

Key Points

- What can be done to stimulate end of life care discussions earlier in patient care?
- What obstacles exist that prevent and postpone these conversations?

Dr. Bernacki presented some initial data from her study (conducted with Drs. Susan Block and Atul Gawande) on the impact of patient/doctor conversations regarding care at the end of life. The study is based on the premise that end of life care is of great value, both significantly improving a patient's quality of life and reducing health care costs. Discussions about end of life happen an average of 33 days before death; the study proposes that it may be important to have these discussions earlier to better engage patients in their care decisions. Earlier discussions about end of life are associated with improved outcomes such as higher rate of hospice use, less hospital use, better stress and bereavement scores from family members, and higher patient satisfaction.

Researchers began by identifying failure points in end of life planning. They identified three key obstacles that break down and prevent end of life conversations from happening: 1) Patients and clinicians don't know how to talk about end of life care; 2) Information about a patient's values and goals are not consolidated in one place; and 3) There is no system for identifying the right patients with which to discuss end of life care.

To address these obstacles the research team put together a 'Serious Illness Care Program.' The conversation guide could be used as a helpful tool for clinicians, giving them words and phrases to use in uncomfortable end of life discussions. It is also a way to force doctors to listen more to patient preferences and goals in their health care. The guide includes seven key questions for clinicians to ask their patients:

For the study, physicians received 2.5 hours of training in using the guide and engaging in end of life care conversations with patients. Patients were considered appropriate for the study if their doctor stated that they would not be surprised if the particular patient died within one year. Researchers then measured patient and doctor reactions to the end of life discussions stimulated by the conversation guide.

Clinical and Patient Perspectives

Discussants: **John Barkley**, Post Acute Care Services Chief Medico Officer at Carolinas HealthCare System

Tina Staley, Co-founder of Reimagine, Co-creator of Pillars4Life, Founding Director of Pathfinders International

<p><i>Key Points</i></p> <ul style="list-style-type: none">- What is needed for a cultural shift in how we understand end of life care?- How can we plan for care at the end of life in a culture of living?
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Dr. Barkley began by commending Dr. Bernacki's study for formalizing information regarding the impacts of end of life care discussions, and offering this information in a format that is accepted by the scientific community. He spoke about how a cultural change in palliative care could be facilitated by research. He suggested that a true cultural shift in how we understand end of life care cannot happen until leaders in the health care system accept this as a necessary part of health care.

Staley emphasized that end of life conversations must be focused on the emotional components of these decisions. Identifying a patient's biggest fears is central to helping them live fully and plan for the last chapter of life. She suggested that we need to plan for care at the end of life within a context of living. This means planning with support, spirit, and hope. She suggested that helping patients identify their greatest fears can help them calm their minds enough to be able to have open conversations about end of life care. Finally she asked, why do we only think about what matters to us most when we are faced with the end of life? And what would it look like to create a culture in which discussions on end of life were part of our daily consciousness?

Patient Education for Aging Populations and Advanced Illness Patients

Presenter: **Geri Baumblatt**, Editorial Director, Emmi Solutions

<p><i>Key Points</i></p>

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| <ul style="list-style-type: none">- Benefits of patient education;- Outline of Emmi Solutions patient education programs. |
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Emmi Solutions has produced over 200 programs for patient education regarding a range of health issues. These programs are used in over 300 hospital systems and care plans. The programs provide patients with information about their health conditions in plain language, using a conversational tone similar to an informed friend, and allow patients to input questions for their doctors about the information presented; doctors can review these questions before appointments. Emmi also provides a series of programs called EmmiDecide, which allow patients to enter information about their values and preferences to help them make decisions about care options. Seniors are one of the largest user groups of Emmi programs. Emmi believes that these programs are necessary for SDM as patients need information before they can know *how* to think about their options. These programs may also help to improve doctor/patient trust as they signal to patients that their doctors want them to be informed.

Emmi has found that their programs reduce patient stress. In a randomized control trial they saw reduced anxiety and improved knowledge in patients who used Emmi programs. They also saw less anesthesia use and quicker procedures. In a user survey,

- 99% of respondents said that Emmi programs helped them to know more ways to deal with their conditions.
 - Baumblatt commented that this may be a reflection on the current medical system in which patients often don't know that they have care options.
- 98% said they had a better understanding of the pros and cons of care options.
- 98% said they thought they could make a better choice after viewing the Emmi program.
- 90% said they could have a better conversation with their doctor after having viewed the Emmi program.

Audience members discussed a number of key issues:

- How do we address the issue of conflict between patients and doctors?
 - One members suggested that shared decision-making is based on a framework of patient autonomy. The patient can decide who has a voice in their decision-making process. If they disagree with their doctor their decision may be to get a new doctor.
- The unfair balance of power between patients and doctors hinders SDM as it encourages patients to please their doctors rather than be seen as 'bad patients.'

Cultural Considerations and New Roles

Presenters: **Ysabel Duron**, Founder of Latinas Contra Cancer and founding member of the National Hispanic/Latina Advisory Council of the Susan G. Komen Breast Cancer Foundation

Deborah Pierce, Board Certified Hospice Palliative Care Physician and Integrative Health Coach

Key Points

- How do we practice SDM in a system that is struggling to deliver even basic care to some populations?
- What are key barriers for minority groups in the health care system?
- What role can health coaches play in facilitating patient communication?
- What is the role of faith, and the faith community in SDM?

Duron began the session by describing the work of Latinas Contra Cancer. The organization works to help Latinos in Santa Clara County, CA receive cancer care. Though the county as a whole is affluent, it includes a large population of low-income, Latino immigrants, many of whom do not speak English. Further, 1/3rd of the Latino community in Santa Clara County is under- or uninsured. As a result of these factors, care is often delayed for this community due to breaks in communication. To combat this Latinas Contra Cancer works to provide culturally and linguistically appropriate information to cancer patients, largely through patient navigation services in the hospital. This support is meant to increase patient compliance and ultimately reduce the cost of care. The organization also works to incorporate patients' cultural and spiritual beliefs into decision-making processes. Latinos place a heavy emphasis on relationship and need time to form trust with their doctors in order to engage in shared decision-making. The current health system does not allow this type of relationship to form.

Ultimately Duron asked, how can we practice shared decision-making in a system that is struggling to deliver even basic care to some populations? She offered the following suggestions to address these obstacles:

- Doctors need to receive cultural competency training in medical school;
- We need an increase in minority doctors who are bilingual and bicultural;
- There needs to be greater following of CLAS (Culturally and Linguistically Appropriate Services in Health Care) standards, as issued by the Office of Minority Health;
- We need to start conversations with Latino communities through trusted leaders

Dr. Pierce began by introducing her care philosophy: in order for patients to die a good death, they need to be empowered by their own choices in their end of life care. The fastest growing cohort of patients in the US today is people over 85 years old. Dr. Pierce

highlighted obstacles in patient/doctor communication. Just because doctors have conversations with patients does not necessarily reflect that communication has taken place. She asked, how do doctors talk to patients so that they will listen? And how do doctors listen so that patients will talk?

Dr. Pierce then introduced some basic tools that she uses in patient communication:

- *Not talking*; instead, asking patients questions that facilitate trust and safety;
- Being fully present and engaged with patients during interactions;
- Trying to have all major stakeholders present during meetings;
- Asking questions that elicit patient values and beliefs.

Dr. Pierce pointed out that a major obstacle to SDM is that doctors often don't have enough time to engage with patients in a meaningful way. Health coaches may offer a solution to this. By partnering with patients, health coaches can develop an awareness of patient core values and can help patients make care decisions that are in alignment with these core beliefs. Dr. Pierce also commented on the role faith plays in the African American community. Often African Americans go to pastors for advice in health decision-making. Dr. Pierce suggested that pastors need to be informed about health care alternatives in order to give patients better advice.

Test Lab for ‘Care at the End of Life’ Discussions

Presenters: **Geri Baumblatt**, Editorial Director, Emmi Solutions

Baumblatt presented a clip from an Emmi program about hospice. She then asked symposium participants to discuss the clip and provide feedback. Participants suggested that the focus of the program should be on what feelings it elicits from viewers. It could more actively engage viewers if they could fast-forward between sections. Programs could also include nurses in some ways, as nurses often realize that a patient is ready for hospice sooner than doctors. Participants discussed challenges in creating voices and scripts that can appeal to all socioeconomic backgrounds. There was also a discussion about the use of personal testimonials in decision aids; Baumblatt commented that IPDAS (International Patient Decision Aid Standards) Collaboration currently recommends against using personal stories as they may be too convincing and unfairly bias decisions (see: <http://ipdas.ohri.ca/IPDAS-Chapter-E.pdf>).

Reflections and Research Directions

Discussant: **Richard Payne**, Ester Colliflower Professor of Medicine and Divinity,
Duke University

Dr. Payne summarized the day’s discussions. He highlighted the following issues:

- A major obstacle to shared decision-making is the transparency of all parties involved.
- We need to be aware of whether decision-making tools subtly usher patients towards certain decisions.
- Finally he asked, how do we think about shared decision-making in the context of people who do not have access to basic healthcare?

Friday, November 15th, 2013: Health Sector Advisory Council & Collaborative on Healthcare for Aging Populations and Advanced Illnesses (HSAC/CHAPI) Meeting

Framework for “Shared Decision-Making” and Current Research Perspectives

Presenter: **Peter Ubel**, Professor of Marketing at Fuqua School of Business, Professor in Public Policy in Sanford School of Public Policy, the Madge and Dennis T. McLawhorn University Professor

Key Points

- Medicalizing the diagnosis of patient preferences;
- Doctor’s ‘ethic of information’ gets in the way of good patient/doctor communication;
- Distinction between general communication, and decision-focused communication.

Dr. Ubel began his presentation by handing out a transcript of a recorded conversation between a patient and a urologist. In the conversation the urologist informs the patient that he has cancer and describes biopsy results. Ubel asked for reactions to the transcript. Audience members found that there was a lack of compassion in the doctor’s tone, an overwhelming amount of information presented using a lot of jargon, and little room for in-depth discussion of the patient’s concerns and questions. Dr. Ubel explained that doctors have assumed an ‘ethic of information’ in which they feel they must present patients with all possible information. Because of this many doctors feel pressure to ‘get through a spiel’ during appointments and present more information than is helpful for good communication. Ubel suggested that it is the responsibility of both doctors and patients to facilitate communication. This could include having doctors focus less on technical aspects and more on addressing patient questions, and allowing for post-appointment debriefs for patients.

Dr. Ubel described the goal of shared decision-making as helping patients receive the care that is in their best interest. This can vary between patients and situations, and depends on patient goals. Eliciting these goals depends on good communication, which is the part of SDM that has not yet been done well. Doctors need to know how to diagnose patient preferences in order to give good advice, tailored to individual patients. Ubel suggested a need to ‘medicalize’ the diagnosis of patient preferences so that this is taken seriously in the medical world.

Communication skills are taught in medical schools, but much of this work is undone during residencies and later medical training. Dr. Ubel suggested that the use of ‘peer-review’ of communication skills between doctors could improve their communication skills. One audience member suggested that there is a difference between general

communication, which is taught in medical training, and decision-focused communication. At this time there is little curriculum to help with learning this second type of communication.

Perspectives on Care Giver Training for Shared Decision-Making

Presenter: **Barbara Sheline**, Board Certified Family Physician, Co-founder and Director of Primary Care Leadership Track, Duke University School of Medicine

Key Points

- Including communication skills in medical school curriculum;
- Encouraging doctor ‘peer-review’ of communication skills;
- Other ways of fostering patient/doctor communication in clinical setting.

Dr. Sheline described Duke Medical School’s two-year practice course on doctor/patient communication. The course is taught by doctors and other clinicians involved in patient care. One of the most profitable exercises in the course is allowing students to watch videos of peers to learn about communication styles. In a capstone course in the final year of school, students are required to role-play interactions with patient family members. One audience member noted that good communication is often what patients consider most important in doctor competency. Unfortunately much of this training may be lost later in the medical career.

Dr. Sheline suggested that doctors are only a piece of doctor/patient communication, and there is a need to get others involved as well. An audience member suggested that ‘experience coaches,’ dedicated to helping patients and doctors communicate well, can help to meet this need. There was also a question of whether medical students should receive career guidance based on their communication skills. Dr. Sheline suggested that perhaps medical schools could learn something from business school curriculum related to communication.

Patient Education for shared decision-making in “acute” and “chronic” illnesses

Presenter: **Geri Baumblatt**, Editorial Director, Emmi Solutions

Key Points

- Challenges to presenting various care options equally;
- Use of feeling and thought exercises in acute illness decision-making;
- Use of SDM to increase patient adherence in chronic illness management.

Geri Baumblatt divided her presentation into two parts, addressing education for both acute and chronic illnesses.

Emmi’s Acute Illness Education Programs

Baumblatt began by showing clips from Emmi programs for prostate and breast cancer. In conjunction with these she showed clips of focus groups Emmi has put on to solicit viewer reactions to the programs. One challenge the Emmi team faced while creating the prostate cancer program was of presenting active surveillance as a legitimate care option, rather than an afterthought to more aggressive treatments. Despite significant efforts in this direction, focus groups continued to feel that the program was biased against choosing active surveillance. In response, Emmi added additional information on active surveillance to give this treatment option more screen time and “weight.”

In the breast cancer focus groups Emmi discovered that most women who had already undergone a procedure for breast cancer reported that they hadn’t known they had a choice between procedures and had been rushed into surgery. Baumblatt discussed how doctors often misdiagnose women’s treatment goals, assuming a woman’s top priority is preserving her breast, while most patients report their priority is getting rid of the cancer.

Emmi includes feeling and thought exercises in their breast cancer program to encourage viewers to imagine concrete life situations after having made either treatment option. Breast cancer focus groups found these exercises very helpful.

Audience Discussion About Emmi’s Acute Illness Programs

The audience discussed some of the pressures patients often feel to choose more aggressive treatment options, such as a high time pressure, rushed decisions, and feeling that they have to compete with other patients for doctors’ time. There was a discussion about whether we should rename some growths to avoid the word ‘cancer,’ as a cancer diagnosis often triggers high anxiety and feelings of time pressure. Renaming things could help patients think through care choices with less anxiety. Audience members also discussed how the medical system may inflate the occurrence of unnecessary procedures as it pressures doctors to fill surgery block time. Finally, audience members noted an opportunity to use the focus group model for patient post-appointment debriefs.

Emmi's Chronic Illness Education Programs

Baumblatt continued her presentation by showing a clip from Emmi's program on diabetes medication choices along with focus groups of people with diabetes discussing the program. Baumblatt explained that patients often feel that they never agreed to take any medication, as patients feel that a second medication indicates that they are somehow failing, and doctors often don't listen to their values. The hope with SDM in chronic illness care is that it could improve patient medication choice to better match their goals, leading to increased adherence. The video worked to describe each treatment option (injections, increased metformin, etc.) with equal detail and to provide information with the intention of engaging patients in their care decisions.

Focus group participants reported that even with the large amount of material presented in the program, they felt able to hone in on their decisions. Baumblatt reported that often patients understand their preferences, but don't necessarily understand what treatment option this translates into. The program allows patients to play with their treatment priorities to understand what care choices their set of preferences indicate.

Audience Discussion Regarding Emmi's Chronic Illness Programs

Audience members brought up the fact that often it takes seven exposures to a piece of information for a person to know it. This may mean that medical education materials need to reinforce options multiple times over the course of an illness. They also discussed how medical scares can increase patient compliance. Because chronic illnesses are not felt all of the time, lifestyle changes can often be difficult to motivate. It may be helpful to give patients an idea of possible trajectories of their illnesses even in early stages of the disease. Audience members asked, should we scare patients in order to encourage them? What are better ways to wake patients up to the realities of their diseases?

Payer and Institutional Perspectives

Presenters: **Betsy LaForge**, Director of Healthcare Program Development for Blue Cross and Blue Shield of North Carolina

Jeff Livovich, Medical Director of Medical Policy Organization for Aetna

Andrew Murray, Cigna Senior Vice President for Strategy and Business Development for the Middle East & Asia Pacific Region

Key Points

- Clients often don't see payers as a trusted source of medical information; who is this trusted source?
- Benefits of fee-for-value vs. fee-for-service models in encouraging SDM;
- Opportunity of Medicaid market to institute SDM model;
- Role of employers in promoting and incentivizing patient engagement.

Betsy LaForge began the conversation by discussing the benefits of shared decision-making in increasing patient compliance; patient involvement improves quality of care and makes utilization of care more appropriate. Research shows that nine out of 10 patients do not receive health information in ways they can understand. Blue Cross offers member outreach by nurses and health educators trained in motivational interviewing and SDM as well as online tools to help provide them with important information. However, member utilization of these tools is not as high as it could be because members may not expect or look for this kind of information, and may in some cases be suspect of this information, coming from their health insurance company. LaForge suggested that this information may be more readily accepted the hands of trusted health advisors, such as doctors and nurses. She also discussed how the current fee-for-service model will never encourage SDM as this model rewards performing more procedures. A fee-for-value model would be better at facilitating SDM. Blue Cross is undertaking many efforts to support patient centered medical homes and provide health services differently.

Jeff Livovich discussed his company's efforts to offer members health coaching and to see the patient as the core person they serve. He discussed how often the Medicaid market may offer the most opportunity to institute patient education plans and SDM. He also discussed how patient responsibility has not been a big part of health care. Livovich suggested that the ACO model might bring great changes to health care in the near future. Finally he commented that chronic illnesses present one of the greatest challenges to incorporating SDM in our health system.

Andrew Murray discussed the obstacles for foreigners to engage in the health care systems of the countries they are visiting. Cigna sees extremely low engagement from the expatriate community in health assessments and healthcare. Murray's work is to facilitate healthcare in foreign environments at a client level. He outlined the five stages of health insurance:

- 1) Critical illness policies
- 2) Supplemental hospital insurance
- 3) Supplemental health insurance
- 4) Benefits of network design to drive utilization behavior
- 5) Managed type plans

Audience Discussion

One audience member asked whether there may be an opportunity to understand the difficulties payers have in connecting with clients. Betsy LaForge responded that while members who do access BCBSNC shared decision-making support services report being very satisfied, most people don't ever access them. She noted that BCBSNC has had more success working at the employer level as employers can promote available educational services and give incentives for employees to complete health assessments and screenings, or use available educational resources and tools. The group discussed the possibilities of offering more incentives to increase patient engagement. A participant also discussed how different payment models can engender member responsibility; for example, models that encourage patients to save for health expenses by having the health company contribute to this fund can increase member buy-in. Finally, an audience member discussed the importance of targeting information to specific markets.

Emerging New Roles

Presenters: **Terri Sullivant**, Fully Alive Life Coach and an ICF certified coach (ACC)

Jeff Belkora, Associate Professor of Surgery and Health Policy at the University of California San Francisco

Key Points

- Role of life coaching in patient empowerment;
- What would a health care system look like that focused on health rather than sickness?
- Role of a 'health corps' in increasing patient education and communication in a clinical setting.

Terri Sullivant began her presentation by talking about power of life coaching in her personal health story. Shortly after her 50th birthday she had a health crisis, which resulted in brain surgery and over two years of intense recovery. By the end of these two years she felt lost and without a sense of purpose and identity. She began working with a life coach from the 48 Days Group; through this experience she was able to reinvent herself, and decided that she wanted to offer to others the opportunities that had been given to her through life-coaching. After training in the 48 Days Program and receiving her ICF certification, Terri began working at the Mosaic Life Center in Kansas City.

The Mosaic Life Center represents seven clinics associated with a hospital in Kansas City. In the mid 2000s the hospital decided to make their health care more about holistic 'life care.' They joined with the Mayo Clinic to reinvent the health care experience. To guide this vision the Center began by asking some 'what if' questions: What if we re-imagined, reinvented, reengineered health care? What if we created a warm and inviting, full-of-life environment where people thought more about being well rather than focusing on being sick? What if we did more than treat symptoms, what if we prevented the problem to begin with? What if we became life care, addressing not only the health of people, but also the aspects of life that affect health, such as career, inner peace, lifestyle, relationships, etc?

Though the Mosaic Life Center has all the regular amenities of a health clinic (primary care, emergency care, same day surgery, etc.), Terri described the atmosphere of the Center as spa-like, full of light, fountains, and vibrant colors. The purpose of this atmosphere is to encourage a focus on being healthy rather than a total focus on illness. The Center works to impact the root causes of human behavior in order to help individuals live life well. Six full time coaches at the Center do transformational coaching, aimed at helping individuals become more empowered and live a life that honors their true desires. Terri described coaching work as very positive and forward-focused, looking at the limiting beliefs that stop clients from making life changes.

Jeff Belkora described a health-coaching model designed to meet patient information and communication needs in a clinical setting. The program was inspired by reports from breast cancer patients that they were receiving conflicting information, as well as struggling to ask questions during appointments, and retain information post-appointment. To address these needs, the UCSF Breast Care Center began the Patient Support Corps program. Since no clinician staff had time to take on additional responsibilities, the Patient Support Corps utilizes pre-medical interns. The interns are trained in administering decision aids to patients in a neutral, non-directive tone with the goal of eliciting a patient's questions. Interns also accompany patients to appointments and take notes to share with patients afterwards. Thus far the program has gotten very strong reviews from participating patients.

Dr. Belkora discussed the expansion of the program beyond UCSF and discussed successful implementation at Dartmouth Medical School with medical students, as well as at Berkeley with undergraduates in pre-health profession tracks. He also noted that health coaching services often present greater benefits for patients with more communication barriers. He suggested that empowering patients and involving them in SDM will lead to a flattening of the hierarchy; while doctors will still hold a position of team leadership, they may not continue to have such an elite, individual hero status. This process may be painful for many physicians.

Health Plan or ‘population perspective’ on shared decision-making

Presenters: **Peter Goldbach**, Health Dialog

Key Points

- How do we deliver SDM in a scalable manner for an entire population?
- What role can decision aids and health coaching play in increasing patient ability to make decisions on preference sensitive health choices?

Dr. Goldbach began his presentation by challenging the notion that patient care is always evidence-based. The notion of share decision-making was born out the idea that by educating patients about their care choices they could make more evidence-based decisions. Studies show that SDM leads to better outcomes for patients, higher patient satisfaction, more informed decision-making, and less decision regret. SDM tools can offer the greatest benefit where there is a wide variation in utilization of health services. Though SDM has become widely endorsed, it is not yet widely practiced. Goldbach posed the question: How can we deliver SDM in a scalable manner to affect a whole population? Health Dialog looks at the needs of a specific population and then provides tailored SDM support.

Goldbach discussed the role of decision aids in healthcare decision-making. He reiterated that while decision aids can help with doctor/patient interactions, they cannot do all the work of SDM. He then cited evidence from the Informed Medical Decisions Foundation that after the use of a decision aide patients show considerable increase in knowledge about their health condition. He also cited research that suggests that nearly 95% of people, across a range of demographics, express that they want to have some input in decisions about their health care.

Dr. Goldbach cited data from a randomized control trial that surveyed 175,000 participants with preference sensitive health conditions. Participants who were offered decision aids and health coaching services saw an average of a 5.3% reduction in total medical expenses for the year. Over 75% of participants reported an improved ability to work with their health care provider; 67% reported improved ability to manage their own condition; and 60% reported feeling more confident. Dr. Goldbach suggested that the true power of patient education programs is even more evident for chronic conditions as this represents a larger slice of the population. Based on the evidence in support of SDM in health care, Dr. Goldbach suggested that providers now see a general intent to shift compensation to fee-for-value as this facilitates SDM work.

Dr. Goldbach then cited results from a study regarding Group Health, a health plan in Washington State. Group Health saw a significant unwarranted variation in care across members. To combat this Group Health decided to expand their distribution of decision aids, focusing specifically on patients making decisions about knee and hip surgeries.

One audience member stated that the way we present data in the field of shared decision-making is very important; in the case of the Group Health study, the data was very difficult to interpret. The title of the article suggested that use of decision aids resulted in a sharp decline in knee and hip surgeries, when in fact study results showed that patients who actually reviewed the decision aids had higher surgery rates. The participant cautioned that we cannot say with assurance that SDM reduces utilization rates and expressed concern about the editorial decisions used to present SDM data as these can increase the potential for misinterpretation and take away credibility for SDM.

Dr. Goldbach continued by asking how we can introduce SDM at the point of care. Many studies show that doctors like SDM not because it changes utilization rates, but because their patients like it and it leads to more successful patient interactions.

Discussants: **Alex Sapir**, Executive Vice President for Marketing and Sales, United Therapeutics

Peter Ubel, Professor of Marketing, Professor in Public Policy in Sanford School of Public Policy, the Madge and Dennis T. McLawhorn University Professor, Duke University

Key Points

- We need a new set of terms to describe ‘value’;
- Patient out-of-pocket costs need to become an explicit part of SDM discussions.

Alex Sapir discussed the challenges presented by discussions of ‘value’ given increases in out-of-pocket costs for patients, and general opacity about actual costs of therapies. He suggested that the terms and vocabulary used by payers and physicians needs to change in order to support good communication. The extent to which new terms are needed may depend on the type of therapy – drugs that are highly expensive and specialized carry a greater PR risk and thus will be prescribed more carefully; drugs that go through pharmacy benefits present a greater need for a more accessible vocabulary.

Peter Ubel noted that it may be problematic if SDM becomes too much about controlling costs. This could lead to selective use of decision aids where the only aids distributed are those regarding health issues in which SDM has been shown to reduce costs. Using reduced cost as a main selling point for SDM may also make physicians less supportive of these tools as they may worry about reduced opportunity for work. We need other incentives for using SDM beyond saving money. Ubel also commented that patient out-of-pocket costs need to be made a more explicit part of SDM. Out-of-pockets costs can often present patients with bigger life burdens than even treatment side effects. While no physician would prescribe a treatment without mentioning the medical side effects, cost side effects are frequently not discussed. There needs to be better information available regarding prices for medicines and treatments, and we need to make physicians more comfortable with having conversations about costs.

The Way Forward: Optimism, Concerns for sharing decisions

All Participants

Jeff Moe began the concluding discussion by asking participants what discussions and information presented over the last two days had captured their imaginations and presented an opportunity to move forward in shared decision-making. Participants took turns offering their insights about the conference presentations. Many comments fell into broad categories, as described below.

How can we increase the availability of high quality information for patients?

- What would happen if high quality decision aids were made available over the counter? What if we had these aids available at the public library? How would this change patient empowerment?
- The FDA's recent mandate to make non-product specific counseling documents available to patients may present a way forward. There have been over 6,000 of these documents ordered within one year, showing significant promise in the role of information availability in empowering patients.
- A participant working for a pharmacy company discussed the difficulties in explaining medical options to patients, particularly with more advanced biologic medicines. These conversations are made even more difficult by FDA restrictions on how much information a company can present regarding other company's products. The participant wondered how doctors and nurses can access information in a way that is helpful
- Another participant representing a tech company discussed his interest in helping customers to gather and analyze data to make their own informed decisions on health care. However, he remained uncomfortable with the ways that clients operationalize these insights. He suggested that we need to find ways to institutionalize time for SDM; this could be driven through the payers.
- The role of health coaching was repeatedly highlighted as a major opportunity for moving forward.

How can we resource changes in health care system to incorporate SDM?

- Belkora's description of the Patient Support Corps was highlighted as a way forward. How could relate to Barbara Sheline's course at Duke Medical School?
- There was a discussion of the difficulties in obtaining funding to educate health practitioners in SDM post-residency, especially as this is not profitable in the immediate term.
- We need to address the provider/patient relationship to more forward. What can we do to support coaches and navigators in the health system?

Many participants commented on the cost saving aspects of SDM:

- Several comments were made regarding the difficulty in making fair promises regarding end of life care. While it is important to be transparent regarding reduced costs, there is also data to show that this is better in terms of outcomes and patient satisfaction.

- One participant commented on the potential of a bundled fees cost model for building SDM into the health care system.

What broad shifts are called for in the culture of our health care system to support SDM?

- The work of Tina Staley, Terry Sullivan, and Geri Baumblatt was highlighted as presenting opportunities for patient empowerment by seeing and treating patients more holistically.
- Multi-disciplinary communication between doctors, nurses, dieticians, psychologists, etc., may be a way forward in promoting patient satisfaction and increasing reimbursement.
- How can we connect SDM to the triple aim: better quality care, population health, and reducing per capita cost of care? If we can draw connections between SDM and these goals we have a basis for dialogue between all stakeholders in the health care economy.
- How can we think more broadly about the role of medicine in our society? Is medicine meant to fix us, or is it intended to maximize human potential? This is important to think about in order to combat much of the paternalism still present in conversations about SDM in healthcare. We need to get to a place where doctors can present the information as they understand it, where cost can be an open part of the conversation, and where patients can think about their own goals and values.
- Another participant picked up on the need to normalize end-of-life discussions; one way forward is to build them into the early stages of health coaching.
- While much of the discussion has focused on patient obligation in SDM, for a real culture shift in our health system we need to educate *everybody*. Incubators, ACOs, and integrated health systems could be a source for this culture change across the board. How do we create a non-biased source of information for everybody?
- A key obstacle to embedding SDM into our health care system is that no one party takes full responsibility for its realization.

Richard Payne offered some concluding remarks to close the symposium. He began by reiterating that the promise of shared decision-making in health care is great. A central obstacle to implementing true SDM is communication. Care decisions are almost never purely intellectual for patients and families, but are emotional and often counter-intuitive. We need communication strategies that take these emotional perspectives seriously. We also need to focus on communication strategies that help providers diagnose patient and family preferences. Better provider communication may be facilitated by peer reviews. Further, we need to carefully consider how conflict can hinder SDM. We need to consider how to manage different perspectives, and differences in values between doctors and patients and families. Finally, Dr. Payne highlighted that while we all want patients to be empowered to take part in their health decisions, there will always be variability in the extent to which patients can do this. It would be counterproductive to hold up goals that are unrealistic for some patients, and put in place policies that penalize behaviors that are not in line with these goals. It will be very important to segment the population so that interventions can be personalized and make sense.