

# Improving Patient Outcomes through Effective Caregiver-Clinician Communication and Relationships Expert Meeting

May 17-18, 2018

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## Meeting Summary

### Introduction

On May 17-18, 2018, the National Academy of Sciences (NAS) Board on Behavioral, Cognitive and Sensory Sciences (BBCSS) convened an expert meeting on the role and impact of caregivers in clinical interactions, which was sponsored by the National Institute on Aging (NIA) Division of Behavioral and Social Research (BSR), at the NAS Historic Building in Washington, DC. The purpose of the meeting was to solicit expert views through formal presentations and open discussion on the gaps in knowledge related to how caregiver involvement in clinical settings affects patient-clinician interactions and relationships and, ultimately, the patient's clinical outcomes and well-being. The meeting was co-chaired by Drs. Terri Fried, Yale, and Douglas White, University of Pittsburgh. This document summarizes the presentations and discussions at the meeting. The meeting agenda and participants list are provided as Appendices I and II, respectively.

Currently millions of older adults in the United States receive support from intimate partners, adult children, and family caregivers and surrogates who are often charged with making critical health care decisions on their behalf. Despite the growing presence of such caregivers in health care settings, the question of whether and how these caregivers impact the quality of patient care and outcomes through influencing the patient-clinician relationship has not been well investigated.

In setting the stage for the meeting, Dr. Melissa Gerald, NIA, acknowledged that meeting discussions would venture into largely uncharted territories, but noted that participants' scientific contributions to their respective fields had directly and indirectly informed the development of the meeting agenda. Dr. Gerald reiterated NIA's interest in identifying research priorities for improving our understanding of the role and impact of caregivers in patient-centered care and the potential need for behavioral intervention development. She also raised the potential of this work for establishing principles for third-party involvement in care delivery, such as those applied in pediatric care.

Meeting co-chair, Dr. Terri Fried of the Yale School of Medicine noted that very little research has been conducted on the triadic patient, clinician, and caregiver relationship and asked the invited experts to clarify the state of the science and to identify issues pertaining to caregiver influences on clinician-patient relationships.

### **A Model of Caregiver/Third-Party Involvement in Clinical Interactions**

*Jennifer Wolff, Johns Hopkins Bloomberg School of Public Health*

Data show that in almost all cases, family members, not paid attendants, accompany elder patients to doctor visits. In recognition of this fact, Dr. Wolff and her colleague Debra L. Roter developed a model to help advance the science and practice pertaining to the triadic patient-

clinician-caregiver relationship.<sup>1</sup> The model, in its original inception included three elements that are central to medical encounters:

1. **Relational rapport**, which refers to trust, empathy, and mutuality to support a productive alliance among all parties. This type of rapport can be difficult to establish when the patient is older, very sick, or has low health literacy or is otherwise socially disadvantaged.
2. **Information exchange**, which refers to the giving and receiving of knowledge about the patient's health, symptoms, values, goals, and treatment. This information exchange is important because the clinician is the medical expert, but the patient is the expert about his or her own life, values, goals, and priorities. When the patient is cognitively impaired or less literate, the caregiver often becomes the information source.
3. **Decision making** that involves a shared understanding is especially relevant to chronic care, where successful treatment depends on patient behavior outside the clinic, with family involvement representing a critical dimension.
4. **Goal setting** was not included in the original framework but was considered a critical element to integrate and discuss in the expert meeting.

Family involvement extends beyond the clinical encounter and can be both beneficial and detrimental to patients. Because evidence is limited on the effects of family involvement on patient outcomes, this area merits further research.

### ***Discussion***

Triadic communication can generally be expected when caring for patients from two distinct populations of older adults—those with dementia who lack communicative and decisional capacity and those with complex health needs such as disability or chronic conditions. The triadic relationship affects intermediate outcomes, such as patient activation and satisfaction with care, and outcomes in terms of health, well-being, and care consistent with patient and family goals. However, intermediate and patient outcomes are not related linearly to the four model elements and can be difficult to decouple. Any model must account for the fact that relationships change over time.

## **The Role and Involvement of Caregivers in Patient-Clinician Relationships**

### **Understanding the Quality of Shared Decision-Making**

*Terri Fried, Yale University*

Conflict is an unintended but important outcome of the triadic relationship, but it has not been examined with quantitative approaches. Existing data about conflict are qualitative (i.e., how the patient views the caregiver's role in the encounter). Goals for the patient's health and

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<sup>1</sup> Wolff JL, Roter DL: Family presence in routine medical visits: A meta-analytical review. *Soc Sci Med* 72:823-31, 2011.

health care can be a source of conflict. For patients with multiple chronic conditions, measurement of a good health outcome can often be subjective. In addition, disagreements can occur about whose goals should guide actions. Dr. Fried suggested that a shared understanding of goals might be an important outcome to include in the construction and analysis of triadic interactions.

Speaking about day-to-day management of chronic illness rather than palliative care, Dr. Fried reviewed a triadic study that posed open-ended questions about care goals to 28 people who were ages 65 or older, had two or more chronic conditions, a primary care physician, and an informal caregiver. Across dyads, and even more frequently across triads, goals were rarely aligned. In a specific example, the study characterized disagreement among the patient, caregiver, and clinician as a “security-liberty trade-off.” The challenge rests in deciding whose goals will prevail.

Noting the dearth of studies on triadic conflict, Dr. Fried described two of the best studies on dyadic conflict in clinical settings. The first surveyed 200 caregivers for older adults evaluated in a geriatric clinic and their physicians. Although 79 percent shared a common goal, only 40 percent agreed on the most important goal. The second surveyed 127 patients with diabetes and their primary care providers. Only 5 percent of dyads had overlap on the top 3 goals, and only 10 percent had overlap on the top 3 treatment strategies. Agreement on the top strategy was associated with high patient self-efficacy in managing diabetes.

Two concepts embedded in the updated Wolff and Roter framework are noteworthy for conflict studies. First, regarding patient outcomes, the idea of “care consistent with goals” is preeminent because that is likely what physicians strive to provide. Second, regarding goal setting, parties may enter encounters with very different goals, underscoring the importance of studying negotiation processes. Discerning the truth about perceived conflict is not straightforward, and defining high-quality triadic communication is a priority.

### ***Discussion***

Separating the patient’s problems from the interpersonal problems of a couple, a triad, or more involved parties poses challenges, especially because the conflict might reflect deeply entrenched and chronic problems and because relationships are dynamic. It is unclear what a clinical encounter can reasonably be expected to change.

Defining “good” communication might be a fruitful research goal given the increasing occurrence of triadic encounters whose dynamics physicians need to better understand to maximize success.

Caregivers would benefit from some orientation and interactional strategies to navigate their new role and relationship with both the patient and clinician. In addition, the term “caregiver” may feel constraining, or even insulting, to people who do not see themselves in that role or to patients who question their need for a caregiver; the field should find new language to refer to this third participant.

## **Strategies to Improve Surrogate Decision Making for Incapacitated, Seriously Ill Patients**

*Douglas White, University of Pittsburgh*

Another clinical setting is the hospital intensive care unit (ICU), where patients receive treatment for overwhelming acute illness. One in four deaths among elderly patients occurs in an ICU or shortly after ICU discharge. The ICU context can shed light on the high-stakes, emotionally laden decisions that occur in many clinical spaces. Dr. White described the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) randomized control trial (RCT), to illustrate an example of an unsuccessful intervention. This RCT examined the impact of communication to improve end-of-life decision-making and to reduce the frequency of mechanically supported, painful, and prolonged dying. Physicians in the intervention group received daily estimates of the likelihood of 6-month survival, outcomes of cardiopulmonary resuscitation, and disability at 2 months, and specially trained nurses elicited and shared with the physicians the patient preferences about life support. Researchers found no effect of the intervention on end-of-life care or costs relative to the controls, who received usual care according to the physician's judgment about the appropriate context and timing of conversations.

In another RCT, a palliative care provider led at least two structured family meetings during which prognostic information and care goals were discussed. About 130 patients and 184 family surrogate decision makers were randomized into the intervention group, and 126 patients and 181 family surrogate decision makers were randomized into the control group. The results revealed no change in treatment intensity, goal concordance, and quality of communication. However, surrogates experienced higher levels of post-traumatic stress disorder symptoms.

These interventions were grounded in the Rational Actor Model, that is, if patients and their surrogates receive accurate information about likely outcomes, they will make optimal decisions based on patient-perceived value of those outcomes. However, this model has been superseded by two decades of decision theory studies showing that strong emotional states, such as anxiety, can impair people's reasoning and decision-making capabilities. To facilitate good decision making, clinicians can help people move from a distraught emotional state to a calmer state that allows for better processing of information. A multicenter RCT used a specially trained Communication Facilitator (a nurse or social worker) to act as a mediator to identify communication needs and resolve conflicts. Although potentially challenging to scale up nationally, this intervention substantially reduced patients' length of stay in the ICU and concomitant costs.

Dr. White also described findings from a forthcoming report on the Pairing Reengineered Intensive Care Teams with Nurse-driven Emotional Support and Relationship Building (PARTNER) Trial. This intervention is grounded in recognition of the importance of both cognition and emotional states in decision making. The intervention positively affected communication quality, as assessed by the surrogates, and produces other positive results,

including reduced length of ICU and hospital stays, mostly among dying patients, and lowered costs.

Knowledge gaps exist in four areas: (1) improvement of end-of-life care with upstream interventions; (2) effective strategies to elicit and construct patients' values from surrogates; (3) scalable methods to teach clinicians communication skills about serious illness, with VitalTalk and Oncotalk as examples of currently existing and effective training programs; and (4) a robust outcome measure for goal-concordant care.

### ***Discussion***

Because scaling up interventions to improve encounters can be challenging, some investigators are developing web-based tools to support preparatory activities (e.g., to prepare families for ICU visits). However, some encounter processes depend on the clinician's understanding and skillful navigation of the preparatory activity and its outputs. Therefore, the clinician's role must be considered in any intervention designed to improve outcomes, and Stage I research, as described in [The NIH Stage Model](#) framework, may need to be conducted to develop these preparatory materials, and added to as part of any interpersonal intervention being developed.

Nurses and other non-physicians can play important roles in fostering communication and supporting families. For example, in pediatrics, most ICUs hold family meetings, which a social worker, nurse, or other additional persons attend. In primary care practices that serve patients with complex conditions, practitioners seek to define who can work to the maximum extent of their license and serve as that additional person. Often it is someone in a lower paid position, such as a family navigator, who is available for providing day-to-day patient support.

### **Maintaining the Patient-Provider Relationship in Triadic Encounters**

*Joshua Chodosh, New York University*

Physicians should approach triadic encounters as a resource rather than a challenge. Research should examine the kinds of structures needed to both facilitate communication and to help physicians better negotiate expectations and to understand relationship goals. Although little research has been conducted on triadic encounters in older adults in clinical settings, a 2012 literature review of 52 studies on triadic communication and decision-making among physicians, adult patients, and adult companions, other than caregivers and proxies, revealed five related factors that impact medical consultations: (1) patient, companion, and consultation characteristics; (2) companion roles; (3) attitudes of patients, companions, and physicians toward companion involvement; (4) attitudes toward, and patterns of, triadic decision-making; and (5) the impact of companion involvement on patient and physician ratings.

Qualitative work is greatly needed to create measurable, quantitative interventions. The TRIO Guidelines for clinicians provide strategies to facilitate effective family involvement in cancer settings, such as being inclusive and welcoming, encouraging attendance, and communicating information carefully, which can be applied equally well in everyday nonclinical settings.

In geriatrics, physicians consider how the environment impacts communication strategies. Issues such as sensory impairment, functional dependency, medical complexity, and power dynamics make geriatric triadic encounters different. Age-related hearing loss is a large untapped area of investigation. Patients with hearing loss often employ a “checking out” strategy, which leads to the physician talking to the engaged companion. Available strategies to deal with hearing loss are not being employed, even in the Veterans Administration where top-quality hearing aids are free. Physicians who treat elderly patients should be prepared to use a Hearing Assistive Device, or HAD, which can transform patient engagement in the triadic encounter.

Dr. Chodosh posed several questions whose answers would inform understanding of communication during triadic encounters:

- **Communication Barriers:** Can we predict under what circumstances communication will be impaired in the presence of another? What are the best strategies for making this determination? What are the best questions to ask the patient and the other member of the dyad?
- **Communication Facilitators:** What are the best strategies for enhancing communication? How do we standardize best practices beyond an educational model? Is there a need for structural interventions to be developed and implemented?
- **Negotiating Expectations:** What are the dyadic expectations? How do expectations differ within and between dyads and why? How do we best solicit these expectations? Does achieving clarity in shared expectations result in better clinical outcomes?
- **Relationship Goals:** How well do we need to understand the relationship between members of the dyad? How do we create/encourage best relationships? Can we assume that we know what is a best relationship? Perhaps more importantly, what process should be created to know relationship goals?

Overall, the clinician’s perspective of the triad influences the encounter. To some extent, relationships will be determined by the patient’s clinical needs. In addition, they will be affected by the communication approaches employed. How different types of relationships impact clinical outcomes remains unknown, making this an area ripe for study.

### **Understanding the Impact of Caregivers in Different Clinical Encounter Settings**

*Jean Kutner, University of Colorado School of Medicine*

Context—defined as the care setting and purpose, acuity of the patient’s condition, and caregiver role—should be considered when studying the caregiver’s impact on the encounter. For example, the dynamics of interactions will differ if the patient is receiving preventive care during a scheduled office visit compared to acute care in an emergency department. Evidence about how and to what extent context matters is mostly anecdotal, revealing a critical knowledge gap. Another gap is understanding whether different conceptual models and approaches are needed for different contexts.

### ***Discussion***

Because one strategy does not fit all encounters, analysis of the elements of encounters (i.e., the context) will inform development of strategies to improve triad dynamics. Context also has implications for the outcomes that physicians hope to achieve from a given encounter. Yet, few data exist that link the elements of triadic encounters to outcomes.

Currently, families are invisible in the context of care delivery. Their participation is generally not recorded, and therefore the ability to assess the impact of their involvement on outcomes, and then develop effective interventions, is lost. Although somewhat separate from the clinical setting, some social support literature has shown that a cohesive family (versus a family in conflict) leads to favorable outcomes, such as patient behavioral adherence. There is a need to develop behavioral interventions that improve communication and interactions among the patient, the medical professional, and third parties to facilitate better medical decision making and better medical outcomes. A broader approach to the clinical encounter is necessary.

### **Lessons Learned from Pediatric Chronic Condition Management**

*Christopher Stille, University of Colorado School of Medicine*

Almost all pediatric care includes triads, which produces parallels with geriatric care. Pediatricians aim to involve their patients in shared decision-making when possible and to allow patients as much control as is safe, feasible, and developmentally appropriate. The pediatrician's role often involves explaining situations to the patient and always requires listening to the patient's parents.

Taking time to assess the communication and decision-making preferences in the triad is important whenever a new physician assumes medical care of a patient. Medical students and residents often do not receive training in clarifying preferences in the critical initial encounter. Cultural differences should be considered, such as the preference for a non-relative to be involved in decision making. In pediatrics, the time dynamic is important because children and adolescents change, so the clinician-patient relationship must be reassessed every few months. In addition, some adolescents are accompanied by a peer significant other who will engage in shared decision making.

The concept of the primary care medical home within the medical neighborhood is important when dealing with chronic conditions. The role of the medical home in communication is bidirectional: to serve not only to communicate preferences to the health care team, but also to "mediate" or "arbitrate" when team members see things differently among themselves or between themselves and patients/caregivers. The medical home's goal is to communicate preferences to the entire medical team. For children with developmental physical disabilities, caregivers serve to fill skill gaps to promote independence.

The GotTransition.org website is useful for understanding how the health care system functions poorly in transitions from pediatric to adult health care. Making structures and policies visible to families, such as checklists for adolescent capabilities at different ages, helps with transitions. After this transition, the caregiver might change—from a parent who is always

present and knows the patient extensively to another caregiver who may be less available and may possess incomplete information about the patient.

### ***Discussion***

An important question is how to achieve participation from all parties in any polyadic intervention. Appropriate training, a supportive structure, and clear implementation procedures are needed if researchers are to create a successful intervention, and to understand what worked, and why.

Although plentiful, decision aids and communication tools are often not used in clinical encounters. An important question is how to motivate physicians in hospitals that serve multi-ethnic and lower socioeconomic status populations to adopt effective communication principles rather than simply checking off boxes in electronic health records. Team care will be a part of the solution, because it enables specialized communication responsibilities.

Whether health insurance plans will cover family meetings is an important consideration. Policymakers must understand the value proposition—both for patient outcomes and health care costs—of physicians taking the time to establish triadic rapport. Existing billing codes could be used to inform such an understanding. Also needed are data on the impact of a good triadic relationship over time on patient outcomes.

## **Summary of Morning Discussions**

*Douglas White, University of Pittsburgh*

Dr. White summarized the presentations along the following themes and topics: goal conflicts; the psychology of decision-making in emotional-laden encounters; activities to prepare for triadic encounters; issues specific to geriatric and pediatric triadic encounters; the need for scalable, teachable interventions; the need for data to support the value of interventions from the payer's perspective; the different clinical contexts; good care principles, such as providing age-appropriate control to patients in pediatrics; embedding interventions in clinics through careful attention to implementation structures; and the need to focus on costs and economics in addition to scientific advances.

Dr. Fried posed three questions for further consideration: (1) What language should be used to describe the third- or fourth-party caregiver in a triadic or polyadic clinical setting? (2) How much knowledge is sufficient to move forward with an intervention, and where are further observational studies needed? and (3) What is the possibility of a consensus among the expert committee members that any intervention might need to be tailored to different clinical settings?

## **Optimizing Communications between Patients, Clinicians, and Caregivers**

### **Considering the Needs and Biases of Patients and Caregivers in Clinician Communication**

*Joan Monin, Yale University*

Family members play a critical role in communicating patient information and in advocating for care, and therefore it could be expected that any biases they have would likely affect patient outcomes. Studies have shown that family proxies consistently report worse patient-related quality of life and functioning for patients with stroke, cancer, tremors, and dementia than the patient does. Formal caregivers can be biased toward shielding family members from difficult information. In dementia cases, it is important for the clinician to know when to talk to the patient or the caregiver; in the early stage of the disease, patients can still communicate their needs and conditions and caregivers sometimes resist being a source of information about the patient.

A study of caregiver bias examined caregiver and patient views on psychological, existential (e.g., meaning and purpose in life), and physical conditions and found caregiver depression to be a major source of negative bias about the patient's condition. Clinicians should assess caregiver well-being as a potential source of negative reporting bias.

Regarding gaps and future directions, Dr. Monin suggested three areas of focus: (1) How clinicians' perceptions of patients' quality of life and symptoms align with informal caregivers' perceptions and patient reports; (2) How formal caregivers' perceptions align with informal caregivers' perceptions and patient reports (e.g., is the formal caregiver motivated to downplay the patient's suffering to ease the suffering of family caregivers?); and (3) How caregivers' health should be screened and protected in the process of patient-clinician communication and medical encounters.

#### ***Discussion***

Caregivers must be prepared for their roles through anticipatory guidance, a topic not well researched. Currently, caregivers are not assessed and screened for depression. In dementia care, tools exist for caregiver assessment, but they are not widely disseminated.

In the triadic model, patients and caregivers may require separate interventions. However, thought must be given to who would implement them, especially given funding and time constraints.

The next generation of physicians could be trained through interventional educational programs to make sure they understand the importance of obtaining and recording specific types of information during the triadic encounter.

The triadic mental model of three people in a room may be incorrect; rather than focusing on individuals, individual *roles*, potentially involving several people, should be part of the model.

## **Understanding and Improving the Quality of Communication with Caregivers on Behalf of Patients**

*Alexia Torke, Indiana University School of Medicine*

Important variables in the triadic encounter model include the setting/situation and communication factors, with the ultimate concern being patient outcomes. Settings include in-patient, out-patient, and others, and situations include a spectrum of patient conditions, from fully intact to fully impaired. Communication variables include such factors as information, emotional support, and the specific challenges of triadic communication. In addition, the role of the caregiver or patient companion is also variable, as are provider, patient, and family factors, such as family members' emotional well-being. The model includes intermediate outcomes of satisfaction with high-quality health care, as well as patient outcomes that cannot be disconnected from family outcomes.

Communication privacy management (CPM) theory posits that individuals feel ownership over their private information and can choose when to reveal or conceal it. When sharing information, the individual expects the recipient to adhere to rules about disclosure to others. Conflicts may arise when assumptions about these rules differ. The issue is especially important when a companion attends a clinical visit. A study involving 123 informal advocates revealed four themes: (1) the dilemma of privacy versus medical well-being; (2) the companion's self-perception as an altruistic supporter; (3) information seeking by the physician; and (4) shared responsibility for decision-making.

Another study that applied CPM theory to 35 surrogates for hospitalized older adults found conflicts over the surrogate's access to information about the patient, as well as physician's demands for access to information about the patient that the surrogate lacked. Future research should account for caregiver roles, needs, and expectations around information exchange.

Dr. Torke and colleagues developed a 30-item Family Inpatient Communication Survey that has been validated in three diverse Midwest city hospitals. Preliminary analysis of survey results has found that emotional support was associated with family anxiety, depression, and posttraumatic distress. There was a suggestion that giving people extensive information without emotional support may increase post-traumatic stress. Calming a surrogate with better information may help him or her make better decisions. Future research should link specific communication strategies to patient outcomes.

### ***Discussion***

Physicians have an ethical obligation to support family members. However, the boundaries of that support should be carefully drawn to avoid legal issues that might arise from providing medical advice or prescriptions to caregivers who are not patients. This raises the question of how much the expert committee should view caregivers as potential patients as opposed to solely instrumental vis-à-vis patient outcomes.

## **Person-Family Agenda-Setting in Primary Care**

*Jennifer Wolff, Johns Hopkins University*

Studies on interventions to more effectively engage families in communication demonstrate that pre-visit strategies are an effective strategy for engaging patients more actively in their care. However, not all patients have the capacity to participate in their care. Patients and physicians strongly endorse involving family to bridge patient communication deficits, but no evidence-based strategies exist for effectively engaging families.

Evidence indicates that patient-family agenda setting can improve the quality of communication in face-to-face visits. In addition, shared access to the patient portal, with caregivers using their own identify, enhances the caregiver's status and role. Simple, scalable strategies could be readily diffused and could improve communication both inside and outside the clinic. The NIA-funded SAME Page Study (R21-AG-049967; NCT#02986958)<sup>2</sup> found that companions of older primary care patients with cognitive impairment are motivated to support patients during medical visits but lack knowledge of patient health concerns and preferences for communication assistance. In this study, patients and caregivers completed a checklist to align perspectives about the patient's health, clarify patient preferences for communication assistance during the encounter, and identify the most important concerns to discuss with the physician. A coded audiotaped measure found that dyads who completed the checklist experienced significantly more patient-centered communication, especially in mainstream primary care clinics, with no effect on visit duration.

Regarding future directions, processes should be evaluated at a granular level to facilitate understanding of the importance of setting and delivery care characteristics. This work will require mixed methods approaches and engagement of all relevant stakeholders (including from the health system) from the outset. The R61/R33 funding mechanisms lend themselves to this kind of developmental work on a different model of patient care.

## **Roundtable Discussion: Characteristics of the Clinician-Patient Relationship and How This Relationship May Be Positively or Negatively Affected by the Caregiver**

*Terri Fried, Yale University, Moderator*

During this discussion, experts commented on the characteristics of the clinician-patient relationship and how this relationship may be influenced by the caregiver.

- Effective communication processes are not always well aligned with stakeholder priorities. Strategies for improved communication must be linked to health outcomes and be cost-effective for system stakeholder buy-in.

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<sup>2</sup> Wolff JL, Roter DL, Boyd CM, et al: Patient-Family Agenda Setting for Primary Care Patients with Cognitive Impairment: The SAME Page Trial. *J Gen Intern Med* 33:1478-86., 2018.

- Physicians face a dilemma when they realize that a caregiver, who is not a patient of their practice, is at risk for adverse outcomes. The Centers for Medicare and Medicaid Services new Conditions of Participation require home health agencies to document interactions with caregivers. Researchers can mine this documentation, which will be available through OASIS, to understand what works and to develop recommendations and/or interventions.
- Studies involving simple interventions, such as the checklist Dr. Wolff described (Appendix III), which is used to align patient and caregiver perspectives on a set of issues, could be criticized as insufficiently mechanistic. Only a body of studies, rather than one study, can build a chain of causes and effects linked to patient outcomes. Effecting change in care practices will require evidence of patient outcomes.
- Interventions that improve quality of care must be considered beneficial, even if their effect on mortality, length of stay, and other metrics cannot be demonstrated.
- At the same time, quality of care may not be the correct outcome to target. Other outcomes might directly relate to key caregiver activities that occur outside the clinic, such as completing forms and bathing patients. Hospice and advanced care planning are feasible settings and activities for studying such caregiver impacts on care. There may be a role for more observational studies to identify relevant processes and outcomes.

## **Roundtable Discussion: Strategies for Leveraging Caregiver and Clinician Strengths for Optimizing Health Outcomes for Older Adults**

*Terri Fried, Moderator*

During this roundtable discussion, experts commented on existing interventions and key components of future interventions aimed at improving triadic encounters.

- The Callahan PREVENT study, which focused on improving outcomes in the dementia context, underscored the importance of supporting caregivers to both improve patient outcomes and caregivers' emotional well-being.
- The Guided Care study, which focused on high-risk older adults and embedded a nurse case manager in primary care and provided caregiver support, did not find positive changes in primary outcomes. The results suggest the need to tailor interventions to specific populations, such as dementia patients, with similar outcome goals. In tailoring interventions, researchers will have to contend with the increasing numbers of adults who present with multiple chronic conditions.
- A tension exists between developing single, broadly scalable interventions versus disease- or phenotype-specific interventions, raising issues of whether to focus on core triadic-encounter caregiver skills or tailored interventions.
- The question was raised as to whether the core elements of dyadic relationships that a physician must pay attention to, across all settings, can be defined; modifications could be tailored to different phenotypes. Alternatively, a set of processes cuts across all settings, such as the process of achieving an explicit shared understanding of the patient's disease and goals and the caregiver's role.

- Development of a domain-based framework for characterizing and assessing interpersonal processes in different clinical settings could be valuable for developing core principles and intervention strategies
- A body of evidence demonstrates that it is possible to characterize high-quality patient-physician communication. The SAME Page study presents a template for broader approaches to developing an intervention aimed at improving communication.
- Many themes raised in the meeting were consistent with the findings of the *Families Caring for an Aging America* report, which highlights implementation challenges and articulates family-centered care as a broad theme that resonates across populations. The meeting topic of triadic communication points to the relevance of interpersonal domains.
- There is a need for clarity about whether the knowledge gaps lie in articulating core principles of effective communication or in translating those principles into interventions and improved outcomes.
- A deeper mechanistic understanding of how an intervention works can be achieved by testing hypotheses about whether an intervention improves specific aspects of communication. This can be done by modifying specific aspects of triadic interactions and determining whether modifications improve outcomes of interest. The aspects of triadic interactions targeted for change must be specified and measured. Intervention studies should be designed to enable researchers to ascertain whether specific changes in communication lead to changes in triadic encounters, and whether it is through those changes in encounters that patient outcomes are improved.
- Studies that include multiple models of family-centered care have described aspects of effective interventions and frameworks and could serve as aids to identify commonalities and exceptions and to build upon existing knowledge. The Stanley pediatrics statement on family-centered care is one example.
- Quantitative positive outcome measures can be gleaned from properly designed randomized interventional studies assessing communications and outcomes (irrespective of relationship backgrounds) and used to develop trainable interventions. For example, not treating the patient as disabled might serve as an intervention. Such work is facilitated by a hypothesis-driven approach and can also provide insights into mechanisms. The strictly observational approach is inherently weaker.
- There are challenges to quantitatively determining the predictive contributions of interpersonal relations on outcomes because the nature of those clinical interactions may be situational rather than typical.

## Summary of Afternoon Discussions

*Douglas White, University of Pittsburgh*

Dr. White reviewed highlights from the experts' presentations. Dr. Monin reminded the meeting participants that attention must be paid to caregivers to improve patient outcomes. Evidence shows that caregiver depression can produce discordant reports from caregivers and patients; a more structured preliminary caregiver assessment might be valuable. Dr. Torke

focused on the importance of appraising the caregiver's role in particular situations and conflicting expectations about information privacy and sharing. Dr. Wolff emphasized shared agenda setting and the potential value of pre-consultation strategies to engage patients and companions. She also highlighted the importance of attending to the granular details of interventions, especially when transferring them from one setting to another. Dr. Gerald stressed the value of assessing the effects of the third-party in a triad and potential mechanisms to account for them. Participants noted that the mechanistic approach, such as the experimental medicine approach, is already employed to develop interventions that target mechanisms that will improve outcomes, with a measurable causal factor required. Such an approach can be utilized within the context of the [NIH Stage Model](#) to develop maximally efficacious interventions that include training materials, so that they are easily transportable to clinical settings.

## **Reflections on Day One Sessions and Discussion of Possible Breakout Session Topics**

Dr. Fried commented that the invited experts were speaking a common language but were doing so using two different paradigms for conducting triadic research. The NIA Stage Model for Behavioral Intervention Development merges the two types of study, although historically each paradigm has been pursued separately.

One type of study isolates the components of an ideal triad and how they translate to health outcomes. This mechanistic behavioral research model is designed to isolate and study causal factors leading to a specific outcome. Another type of study begins with a clinical problem. To solve the clinical problem, researchers employ assumptions about mechanisms, although as a secondary focus. From the outset, this study must consider context, which does not influence the mechanism but wholly determines how it is incorporated into a successful clinical study.

### ***Discussion***

Both types of research are valuable; however, researchers must be clear about whether their focus is on identifying and assessing mechanisms. The two types of studies do not have to be separated. Some study designs have tested the value of components in influencing clinical outcomes. Large clinical trials generally do not focus on mechanistic questions; however, prior mechanistic research should have explored the reasons why interventions were effective in changing factors of interest.

Mechanism can be described at any level of analysis, including the interpersonal and contextual or institutional level. At the individual level, emotion-related measures can be collected and mechanistically assessed vis-à-vis an intervention and outcome. At the interpersonal level, specific communication processes or styles can be assessed and targeted by an intervention.

Work has been done on the family as a therapeutic agent, which is an incredibly complex process involving interactions among three or more parties. A taxonomy of study types might be possible, such as mechanistic studies examining the malleability of specific individual or interpersonal processes, studies on the family role as therapeutic, and studies on the influence

of context. A list of putative important mechanistic elements might be useful. Interdisciplinary research, an NIA goal, will be critical. Pepper Centers provide a model of successfully fomenting interdisciplinary communication.

## **Breakout Sessions**

Prior to the breakout sessions, experts shared their perspective on key gaps or challenges in the field. They identified the following gaps: (1) behavioral interventions that provide caregivers with guidance for effectively participating in triadic encounters, together with a negotiated agreement between the caregiver and the patient on the caregiver's role; (2) the clinician's perspective on meaningful measures; (3) understanding of effective third-party engagement in different clinical encounters; (4) definitions of interventions to improve each participants' effectiveness in a clinical encounter; and (5) rules defining who should speak and when, as well as clear communication of medical information.

Experts explained that challenges exist in the following:

- measuring polyadic interactions;
- balancing the tension between this meeting's focus on specific process measures for improving communication and the ability to change those measures and relate them to outcomes that matter to stakeholders;
- defining the unit of analysis, such as the family as therapeutic agent, the triadic relationship, or some other unit;
- developing a taxonomy of caregiver functions and a toolkit that defines researchable issues as a foundation for a best practices model;
- proving the value of adopting agreed-upon principles for ideal triadic encounters in influencing targeted outcomes;
- teasing out an intervention's influence on outcomes from the many other factors that influence outcomes;
- measuring the alignment of participants' goals and whether the care provided comports with the goals;
- reconciling conflicting or uncertain interpretations of the meaning of measurable changes resulting from interventions.

Participants were divided into two groups to design a prospective study to address one or more knowledge gaps identified during Day 1 of the meeting. Both breakout groups designed studies centered around goal-alignment processes. The first breakout session group designed a study of a behavioral intervention to promote concordance in setting care goals and for achieving goal-alignment among providers, patients, and caregivers to prevent falls in older adults. The second group discussed challenges related to diabetes management, which generally requires an interdisciplinary team approach.

Observations and remarks made by breakout session participants included the following:

- Patient and caregiver confidence in achieving a goal, subjective well-being, and the degree of goal achievement are important variables to consider. Trust is critical for achieving goal-alignment.
- Many relational factors can influence care goals.
  - Any study would need to be attentive to evidence of differences, good or bad, associated with changes in relationships and the causes for such differences.
  - In analyzing interactions, some factors are measurable, for example, whether dyads' concerns were elicited or spontaneously expressed. A frequency table could be developed to record time devoted to patient examination vs. time spent interacting with the patient and/or caregiver and the direction of these interactions.
  - Goal alignment is not routinely captured during clinical visits.
  - Physician training is required.
  - Physicians may already be too busy to assume an additional triadic role.
- A gold standard for dyadic interactions remains undefined; often, clinician-patient encounters do not go well.
- The amount of evidence needed to advance to an intervention is unclear.

## Recommendations

- Assessing the direct impact of goal alignment on primary health outcomes is challenging and requires consideration and assessment of both primary outcomes and secondary outcomes (i.e. reduced family conflict, changed dyadic interaction, and lower caregiver stress).
- Caregivers need to know what to expect when entering an unfamiliar triadic encounter. Their roles vary significantly depending on the context, such as an emergency room or a nursing home.
- Relational factors must be measured to assess their impact.
- Strong evidence and theory about high-level patient-clinician interaction exist, but measuring and defining strategies to improve the impact of third parties remain challenging.
  - Elements of communication that affect patient outcomes must be identified.
  - Studies of social influence and group dynamics could be useful for mining information on measures, including tools used and post-clinic outcomes.
  - Establishing metric standards for effective triadic communication is critical.
- The NIH Stage Model, especially when combined with the experimental medicine approach, can be a useful conceptual framework for the development of interventions to improve patient outcomes.

## Appendix I: Agenda

**May 17, 2018**

**8:30 a.m.**      **Sign-in and Badge Pick-up**

**9:00**            ***Welcome to the National Academies***

Barbara Wanchisen, Director, BBCSS

**9:05**            ***Introductory Remarks from the National Institute on Aging***

Melissa Gerald, Division of Behavioral and Social Research

**9:15**            ***Setting the Stage for the Meeting***

Terri Fried, Yale School of Medicine

Douglas White, University of Pittsburgh Department of Critical Care Medicine

**9:35**            ***A Model of Caregiver/Third-Party Involvement in Clinical Interactions***

10-minute overview, followed by open discussion

Jennifer Wolff, Johns Hopkins University

**10:15**            ***The Role and Involvement of Caregivers in Patient-Clinician Relationships***

10-minute presentations from invited experts, followed by open discussion  
guided by the questions below.

- How and in what ways does caregiver input support the development and maintenance of patient-provider relationships, shape shared decision making, and influence patient-centered care and adherence?
- What is the optimal role of the caregiver in making decisions when patients are able to participate in the decision-making process? What is the optimal role of the caregiver in making decisions when patients are unable to participate in the decision-making process and what are the optimal outcomes of this process?
- How are goals established in shared decision-making situations, and how can we measure outcomes and their alignment with goals?
- How and to what extent should clinicians intervene, to negotiate and/or mediate, when patients and caregivers or multiple caregivers have conflicting care expectations, beliefs, preferences, wishes and goals?
- Do existing clinician-patient communication principles and models and methods for patient-centered interviewing adequately take the role and impact of caregivers into account, or are new, caregiver-specific or caregiver-centered strategies warranted?

*Understanding the Quality of Shared Decision-Making*  
Terri Fried, Yale University

*Strategies to Improve Surrogate Decision Making for Incapacitated, Seriously Ill Patients*  
Douglas White, University of Pittsburgh

*Maintaining the Patient-Provider Relationship in Triadic Encounters*  
Joshua Chodosh, New York University Langone Health

*Understanding the Impact of Caregivers on Adherence to Patient Preferences*  
Jean Kutner, University of Colorado School of Medicine

*Lessons Learned from Pediatric Chronic Condition Management*  
Christopher Stille, University of Colorado School of Medicine

**11:05**      **Break**

**11:20**      ***The Role and Involvement of Caregivers in Patient-Clinician Relationships, continued***

Moderator: Terri Fried

**11:50**      ***Summary of Morning Discussions***

Douglas White

**12:05**      **LUNCH (Available for purchase in lower level refectory)**

**1:15**      ***Roundtable Discussion: Characteristics of the Clinician-Patient Relationship and How this Relationship May Be Positively or Negatively Affected by the Caregiver***

Moderator: Terri Fried

**2:00 p.m.**      ***Optimizing Communication between Patients, Clinicians and Caregivers***

10-minute presentations from invited experts, followed by open discussion guided by the questions below.

- When are patient-centered or family-tailored intervention strategies most effective for improving communication during healthcare encounters and for developing and maintaining strong and supportive relationships with clinicians? Are specific strategies warranted for patients who have multiple caregivers and/or multiple medical care providers? Are adequate safeguards in place to ensure protection of caregivers in these encounters?
- What models exist to guide and promote high-quality communication among clinicians, patients, and caregivers, and how can we measure the quality of communication?

*Considering the Needs and Biases of Patients and Caregivers in Clinician  
Communication*

Joan Monin, Yale University

*Understanding and Improving the Quality of Communication with Caregivers on  
Behalf of Patients*

Alexia Torke, Indiana University School of Medicine

*Communication and Shared Agenda-Setting*

Jennifer Wolff, Johns Hopkins University

**3:00**            **BREAK**

**3:15**            ***Roundtable Discussion: Strategies for Leveraging Caregiver and Clinician  
Strengths for Optimizing Health Outcomes for Older Adults***

Moderator: Terri Fried

- What models exist to guide clinicians to optimally involve caregivers in health care for older adults while fostering or maintaining strong and positive clinician-patient relationships?
- How can clinicians and other health professionals assess whether there is sufficient support for the caregiver to make informed decisions and provide care in the home?
- What aspects of clinician communication may be responsive to intervention (i.e. modifiable risk factors for unproductive/ineffective communication and/or dysfunctional relationships.)?

**4:00**            ***Methods and Measurement Strategies for Examining Processes and Outcomes  
of Interest***

Moderator: Terri Fried

**4:45**            ***Summary of Afternoon Discussions***

Douglas White

**5:00**            ***Overview of Day Two and Discussion of Possible Breakout Session Topics***

Terri Fried

**5:15**            ***Adjourn Day One***

**May 9, 2017**

- 8:45**            ***Reflections on Day One Sessions and Discussion of Possible Breakout Session Topics***  
Invited experts will be asked in turn to speak for up to 5 minutes offering their reflections on the prior day's discussions and identifying a question they see as critical to address in the near term related to the role of caregivers in decision making and health promotion and the study methods and approaches and measures used for data collection and variables of interest for data analysis. The group will collectively decide on the three highest priority questions, and each question will be assigned to a breakout group.
- 10:15**            ***Setting the Stage for Breakout Session***  
Terri Fried
- 10:30**            ***Breakout Session: Design a Prospective Study to Address One or More Knowledge Gaps Identified During Day One***  
Participants will be divided into smaller groups to design a prospective study that addresses a key knowledge gap discussed during the meeting.
- 12:00 p.m.**      **LUNCH (Available for purchase in the lower level refectory)**
- 12:45**            ***Reports from Breakout Groups and Discussion of Proposed Studies***  
**1:45**              ***Synthesis and Next Steps***  
Douglas White
- 2:15**              ***Closing Remarks***  
Terri Fried  
Melissa Gerald
- 2:30**              ***Adjourn***

## **Appendix II: List of Participants**

### ***Invited Experts***

Joshua Chodosh, New York University  
Terri Fried, Yale University  
Jean Kutner, University of Colorado School of Medicine  
Joan Monin, Yale University  
Christopher Stille, University of Colorado School of Medicine  
Alexia Torke, Indiana University School of Medicine  
Douglas White, University of Pittsburgh  
Jennifer Wolff, Johns Hopkins Bloomberg School of Public Health

### ***National Institute on Aging (NIA)***

Melissa Gerald, Division of Behavioral and Social Research (BSR)  
John Haaga, BSR  
Jonathan King, BSR  
Lisbeth Nielsen, BSR  
Lisa Onken, BSR  
Dana Plude, BSR  
Marcel Salive, Division of Geriatrics and Clinical Gerontology

### ***Board on Behavioral, Cognitive, and Sensory Sciences***

Adrienne Stith Butler  
Thelma Cox  
Garret Tyson  
Barbara Wanchisen  
Tina Winters

### ***Other NIA Attendees***

Partha Bhattacharyya, BSR  
Prisca Ndella Fall, BSR  
Elena Fazio, BSR  
Laura Major, BSR  
Lyn Neil, BSR  
Emerald Nguyen, BSR

## Appendix III: Simple Intervention Example Person-Family Agenda-Setting in Primary Care

### Making the most of your visit

This conversation guide is for patients who attend primary care visits with a family member or friend. Together, use this guide to prepare for today's visit.

**STEP 1 How can your family member or friend be most helpful today?**

*Together, decide what types of help you would like. Mark (✓) all that apply:*

- Listen to what your provider says and take notes.
- Help you understand what the provider says or means.
- Remind you to ask questions or tell the provider your concerns.
- Ask questions or give the provider information.
- Allow you time alone with the provider for some or all of the visit.

**STEP 2 What do you want to discuss with your provider today?**

*Together, decide which concerns are most important.*

<i>Issues affecting the patient</i>	Mark (✓) if a concern to:	
	PATIENT	FAMILY
Hearing or vision	<input type="checkbox"/>	<input type="checkbox"/>
Fear of falls, dizziness, or balance	<input type="checkbox"/>	<input type="checkbox"/>
Bladder or bowel problems	<input type="checkbox"/>	<input type="checkbox"/>
Safety at home or when driving	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty bathing, dressing, or walking	<input type="checkbox"/>	<input type="checkbox"/>
Financial matters that affect patient health	<input type="checkbox"/>	<input type="checkbox"/>
Planning for serious illness or progression of current illness	<input type="checkbox"/>	<input type="checkbox"/>
Changes in personality or behavior	<input type="checkbox"/>	<input type="checkbox"/>
Stress, worry, or feeling sad or blue	<input type="checkbox"/>	<input type="checkbox"/>
Trouble concentrating or making decisions	<input type="checkbox"/>	<input type="checkbox"/>
Memory problems	<input type="checkbox"/>	<input type="checkbox"/>
Managing or taking medications	<input type="checkbox"/>	<input type="checkbox"/>
Add other issues: (optional)	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>

Attachment D1, Version 4, June 26, 2016. Involving Family to Improve Communication in Primary Care; Protocol Application No.6837; PI: Jennifer Wolff.

Source: Wolff JL, Roter DL: Family presence in routine medical visits: A meta-analytical review. Soc Sci Med 72:823-31, 2011.