A Learning Loop Model of Collaborative Decision-Making in Chronic Illness

Sarah D. Ronis, MD, MPH; Lawrence C. Kleinman, MD, MPH; Kurt C. Stange, MD, PhD

From the Department of Pediatrics, Case Western Reserve University, and UH Rainbow Center for Child Health and Policy, UH Rainbow Babies and Children's Hospital, Cleveland, Ohio (SD Ronis); Department of Pediatrics, Rutgers Robert Wood Johnson Medical School, New Brunswick, NJ (LC Kleinman); and Center for Community Health Integration, Department of Family Medicine & Community Health, Department of Population & Quantitative Health Sciences, Department of Sociology, Case Western Reserve University, Cleveland, Ohio (KC Stange)
The authors have no conflicts of interest to disclose.
Address correspondence to Sarah Ronis, MD, MPH, Department of Pediatrics, UH Rainbow Babies and Children's Hospital, 11100 Euclid Avenue, Mailstop MCCO 6036, Cleveland OH, 44106 (e-mail: sarah.ronis@UHhospitals.org).
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ABSTRACT

Shared decision-making is a core attribute of quality health care that has proved challenging to implement and assess in pediatric practice. Current models of shared decision-making are limited, including their capacity to incorporate multiple stakeholders; to integrate downstream effects of subacute or minor decisions; and to account for the context(s) in which such decisions are being made and enacted. Based on a review of literature from organizational psychology, cognitive sciences, business, and medicine, we propose an iterative decision-making model of care planning and identify targets at several levels of influence warranting measurement in future studies. Our learning loop model posits the relationship between pediatric patients, their parents, and their clinicians as central to the collaborative decision-making process in the setting of chronic illness. The model incorporates the evolution of both context and developmental capacity over time. It suggests that "meta-learning" from the experience of and outcomes from iterative decision is a key factor that may influence relationships and thus continued engagement in collaboration by patients, their parents, and their clinicians. We consider the model in light of the needs of children with special health care needs, for whom understanding the ongoing iterative effects of decision making and clinician−parent−child dynamics are likely to be particularly important in influencing outcomes.

KEYWORDS: care planning; children with special health care needs; collaborative decision-making; doctor−patient relationship; family-centered care

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WHAT'S NEW

We propose a novel, dynamic, iterative model of collaborative decision-making for chronic condition management that accounts for the impact of ongoing shared learning on 1) the evolving relationship between clinician and patient/family, and 2) subsequent decision-making.

"SHARED DECISION-MAKING" (SDM) describes the process whereby clinicians first assure patients are well-informed about potentially appropriate treatment options and their range of expected outcomes, then engage with them in participatory decision-making. Reasonable options exist when there is meaningful uncertainty regarding the expected outcomes of different approaches or when the value of those outcomes is sensitive to patient and family preferences. As a means of integrating patient preferences into health care delivery, SDM increasingly is being incorporated in health care organizations and national surveys as a core attribute of quality.[1,2] Over the life course, the impact of medical decisions for children may accumulate synergistically. In general, children with special health care needs—those who suffer functional or health care consequences from chronic illness[3]—would be expected both to have more medical decisions and to be more sensitive to their impacts than children without chronic illness.

Observational studies suggest that most pediatric decision-making is not shared[4,5] and rarely directly involves the child.[6-8] The field recognizes that current models of SDM are limited in their capacity to 1) incorporate multiple stakeholders, 2) consider the downstream effects of subacute or minor decisions, and 3) account for the context(s) in which such decisions are made and enacted. Thus, interventions based on these models are limited, often focusing on single decisions.[9-14] Experts in medical decision-making agree that there is an acute need for "new models of collaborative decision making that are adaptable to children of different ages and flexible enough to accommodate multiple decision stakeholders."[15] To advance health care, especially for those with special

health care needs, models need to account for the accumulated impact of a series of decisions made over time.

In this paper, we therefore propose an iterative model of decision-making in chronic illness, focusing on the relationships among the various clinician and family participants involved in clinical decision-making. We consider these participants to function as a complex system comprising patient, their parent(s), their family context, the clinician, and the broader clinical team, as shaped by the clinical context. In this paper, we abbreviate this complex system as "clinician−family dyad," even as we recognize the diversity of participants. Moving beyond single decisions, the model also speaks to the formulation and implementation of care plans. We assert that decision making is not simply an end in itself but one component of a dynamic process with outcomes that are both clinical and relational.

METHODS

To inform the development of the model, we began with a scoping review of the medical and cognitive sciences literature, following the Arksey and O'Malley framework[16] to answer the overarching question, "What has been broadly published in the literature about communication, negotiation, and trust in collaborative decision-making among children, their parents, and their clinician?" We searched publications indexed in Ovid MEDLINE, CINAHL, Embase, and PsycInfo for the terms "decision making," "patient participation," "negotiating," "collaboration," "empathy," "trust," "physician−patient relations," and "parents," "children," "pediatrics," and/or "pediatricians." Database searches were completed August 4, 2017, and included literature indexed through July 5, 2017. This strategy yielded an initial set of 2088 unique papers plus 70 papers identified via hand-search of the references from key literature. Full-text review was restricted to those English-language articles that described decision theories frameworks or collaborative models that involved at least 1 health professional and 1 patient and/or her caregiver. This process yielded a final set of 42 papers.

The multidisciplinary author team reviewed the papers and their own experience with clinical care and health care system organization. After recording the key participants in the phenomena of SDM, we began detailing the relationships between these players, iteratively refining the connections and model elements, informed by the literature reviewed. We shared early drafts of the model with groups of researchers, clinicians, and families, and continued to expand and consolidate the model. We also presented drafts at professional meetings and made refinements based on that input. We further applied the model to a clinical scenario and research planning to illustrate its value.

RESULTS: PEDIATRIC DECISION-MAKING AND THE ADVANCES AND LIMITATIONS OF PREVIOUS MODELS

First entering the literature in 1982,[17] SDM is characterized as a process based on mutual respect and partnership to choose between alternate potentially appropriate courses of action. Yet, more than 2 decades later, Makoul and Clayman[18] found that there was still "no shared definition of SDM." Common elements include participation of both clinicians and patients, the goal of a plan congruent with family values and consistent with available evidence, but SDM models vary in the degree to which they consider elements beyond those features.[18-20]

SDM models require patients and clinicians jointly to bring evidence into the decision. Preceding considerations of evidence, someone must identify that a decision needs to be made.[11,13] Evidence must be presented in a way that is pragmatic for the decision maker(s) and highlights which data are most relevant to the decision at hand. Available information, including potential clinical trade-offs, should by synthesized, discussed, and its relevance to the current situation assessed. Only then can the decision be made.[21-23] Our review finds that most SDM models focus narrowly on this sequence, considering single decisions (eg, surgical vs medical management). Few models attend to the impact of those decisions on subsequent rounds of decision-making or on advancing or harming relationships.

The Maternal and Child Health Bureau of the United States Health Resources and Services Administration, the American Academy of Pediatrics, and others endorse SDM as a key component of quality health care for children with special health care needs.[22] The Maternal and Child Health Bureau of the United States Health Resources and Services Administration's National Survey of Children's Health generates nationally representative estimates in the United States and assesses SDM as follows: "Among those who needed to make a decision about their child's care in the past 12 months, the proportion who report that their clinicians usually or always 1) discussed the range of options, 2) made it easy to raise concerns or disagree with recommendations for the child's health care, and 3) worked with the caregiver to decide together which health care and treatment choices would be best for the child."[24] By asking what process is typical, this framing hints at the clustering of behaviors inside a relationship. Still, the National Survey of Children's Health neither treats relationships as central nor explicitly identifies that decisions are iterative processes. The SDM data are only available if the respondent self-identifies the need to make a decision, something that occurs for barely more than one half of children with special health care needs in the survey and is more likely for specific high impact than for routine decisions.[24]

Elwyn et al[25] propose a broader conceptualization of SDM (called "collaborative deliberation"). Elwyn articulates a wider set of consequences operating across multiple levels (interactional, organizational, and system) at varying degrees of proximity but fails to integrate the impact of iterations or learning on subsequent decision-making. Sepucha and Mulley[26] incorporate interactions between various levels, such as health care organization and clinical team (including skills in SDM) with patient and family preferences, while still centering on individual clinical encounters. Their model does recognize

intermediate outcomes as input into future decisions, although they do not incorporate their effect on clinician−family relationships. Other well-cited models[27-30] that acknowledge that decisions may evolve iteratively formulate the connections between SDM concepts as linear and step-wise. In sum, we find that current models provide minimal guidance for how decision-making for chronic conditions may evolve over time, where multiple seemingly small individual decisions may accumulate, impacting patient and family for better or for worse.

SYNTHESIS: THE LEARNING LOOP MODEL (LLM)

Health care increasingly is complex and continuously changing and thus best served by flexible and adaptive models for decision-making. The Institute of Medicine's concept of "learning health care systems," which views parents and families as important participants in the learning health care team, suggests a starting point.[31] We propose the LLM, which conceptualizes health care as an iterative system of care in which the shared and distinct experiences of clinicians and families represent feedback that inform all future encounters. The model favors SDM as a process that both generates and incorporates opportunities for continuous learning within the microsystem of child, parent, and clinician (or clinical team). The model situates the relationships in the clinician−family dyad as the backbone for a collaborative decision-making system. The Figure illustrates the LLM.

The parent, child, and family are at the center of the LLM. They bring to the health care encounter a perspective informed by lived experience in the context of their family and community. Their preferences, values, and capacity reflect their access to or gaps in necessary resources that contribute to health. Key variables characterizing the influence of the parent, child, and family context on the learning loop include child-level factors (eg, age, condition, health status, comorbidities and their consequences, developmental capacity) parent-level factors (eg, age, health status, health literacy), and family-level factors (eg, family structure, culture, dynamics between parent(s) and child, socioecological context of health). As the child develops capacity, decision-making authority may evolve from the parent toward the child, thus altering both decision processes and the nature of learning.

The clinician, clinical team, and practice setting bring expertise and clinical judgment into the learning loop. Key variables include clinician-level factors (eg, training, experience, communication skillset, and cultural competency), clinical team-level factors (eg, composition roles and skillsets of team members, processes for team communication, collaboration, coordination, and accountability) and practice-level factors (eg, practice type and setting, friendliness and accessibility of the nonclinical office staff, population served, organizational structure, financial arrangements, organizational culture).

Interactions between clinician, office staff, and family generate a relationship: the extent to which a therapeutic

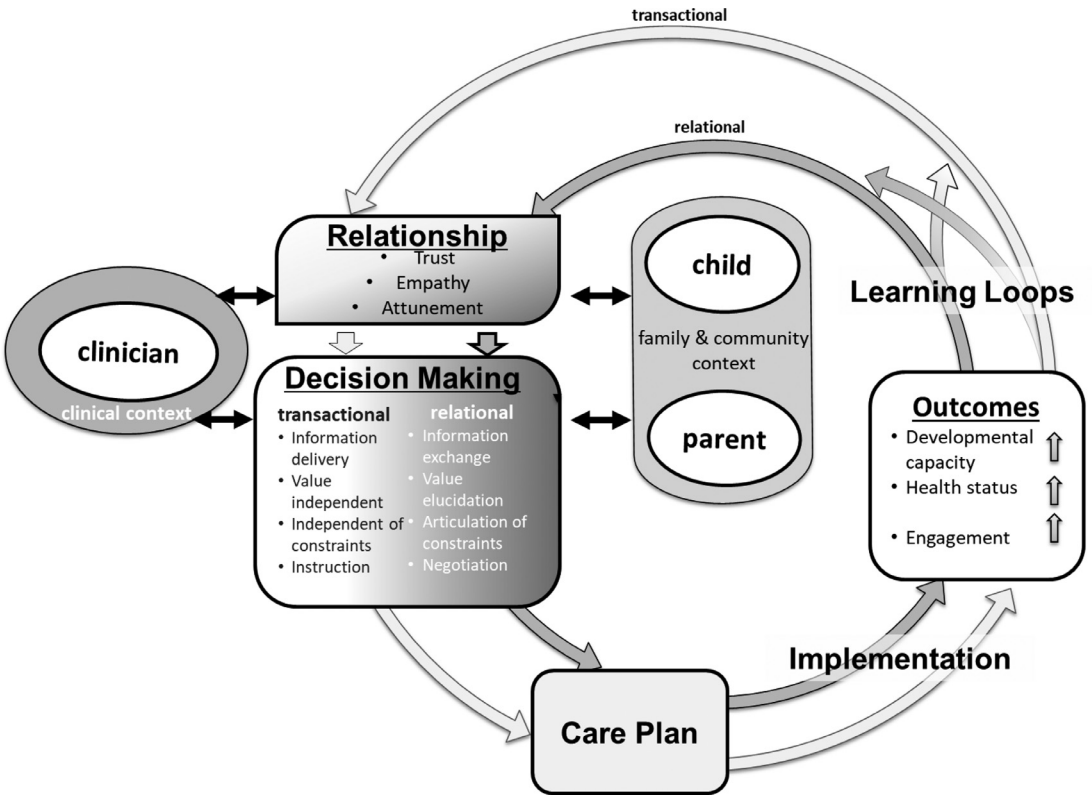

Figure. *A learning loop model of collaborative decision making in chronic illness. Two-dimensional representation of a dynamic system operating in 4 dimensions (including time): learning loops from previous decision-making cycles exert direct effects on the relationship among clinician, child, and parent(s)/family, with aspects of that relationship bidirectionally influencing and influenced by the participants, as indicated by double-headed arrows.*

connection is formed among the clinician−family dyad is related to the extent to which mutual trust and relational empathy are established.[32-35] Key measures of this domain therefore capture each parties' perceptions of relational empathy, situational awareness, and cultural concordance.[20,36-39] Outcomes of clinical decisions, including the extent to which unexpected outcomes occur can be critical inputs. Time is an essential consideration here: we hypothesize that longevity of the relationship and experience of previous shared decisions have important influences on the dynamics of the clinician−family dyad. Greater-stakes decisions, such as for surgery, or threatened loss, may amplify emotional investment and impact of specific shared experiences, thus reducing iterations needed to generate relationship tensile strength that otherwise would be layered over time.[40] Relationships also imply that continuity matters: understanding the structures and processes that influence continuity may be central to understanding the relationship between clinician and family.[41]

The act of decision-making may be circumscribed in a clinical encounter, or occur outside of the clinic, eg, taking or not taking a prescribed medication. Key attributes of decision-making identified in the literature include decision readiness,[42,43] elements of choice talk,[2] and measures of decision satisfaction.[44] Ideally, decision-making incorporates both the strength and relevance of the available evidence.[45-47]

Decision-making typically generates a formal or informal care plan that serves as a "boundary object,"[48] articulating the anticipated actions to be taken by each party, and allowing all parties to reflect on the decision and to revise the plan accordingly. Key attributes of the care plan include the communication tools available to all parties and the composition and complexity of the care team, which may extend beyond the bounds of the practice and family to incorporate other partners who must enact the plan, such as home nursing, ancillary therapists, teachers, and child care providers.

Decisions result in outcomes for the child, family, and health care system. In addition to well-accepted proximal (decision regret, adherence)[23,49] and distal (morbidity, utilization, health status) measures, clinicians, researchers and health care system planners can benefit from considering the extent to which participation in the decision-making process promotes skill-building, the influence of such skill-building on the developmental capacity of child, and the extent to which further engagement by patient and parent is either promoted or impeded. Together these outcomes constitute infrastructure for future decisions.[46]

Importantly, each iteration of interactions, processes, and outcomes from decision-making generates a learning loop. That is, the experiences of the clinician−family dyad, and their understanding resulting from the care plan as enacted, may either deepen engagement in collaboration (following a relational loop) or prompt disengagement by one or more members of the clinician−family dyad (shifting to a more transactional loop). Attending to the "meta-learning" embedded in learning loops about the relationship and the decision making process itself may help researchers assess how decision-making for chronic disease management iterates over time. Key measures related to learning loops include intercurrent events (policy, seasonality), cycle time, quality and completeness of communication, and team learning. Shorter or swifter loops may have differential impact on relationship and subsequent decision making when compared to longer iteration periods.

APPLICATION OF THE MODEL: A USE CASE

R.J. is a school-aged child with a history of mild intermittent asthma who presents with behavior problems at school. His family context is notable for a low-income, single parent who works 2 jobs to afford a subsidized apartment and is without local family support. R.J. presents to initiate primary care after several visits to the emergency department in the past year for his recent-onset asthma exacerbations. Previous health care experiences as a patient and a mother have left R.J's mother dissatisfied, feeling rushed, and not heard.

LOOP 1

In the absence of pre-existing trust, R.J. and his mother are greeted warmly by the office staff, provided time by the clinician, who takes time to elicit the history as RJ's mother frames it. R.J.'s mother reports multiple phone calls from school regarding disruptive behavior in the classroom and a recent in-school suspension. Responding with empathy, the clinician suspects attention deficit−hyperactivity disorder (ADHD) and suggests additional evaluation. Aware of the lack of pre-existing relationship, she uses a nonjudgmental exposition and transactional communication-style to share information with R.J. and his mother, and proposes an initial care plan, including meeting with the practice's health educator both to have R.J.'s mom fill out an ADHD assessment tool and to teach R.J. and his mother a mindfulness strategy to manage frustration. The care plan also includes a request for information from teachers and a referral for outpatient counseling. R.J. and his mom are sufficiently engaged that they meet with the educator, and R.J. tries implementing the mindfulness strategy at school, resulting in fewer class disruptions. While R.J. does not start counseling, he and his mom return for scheduled follow-up.

LOOP 2

The situation is somewhat improved, and perceiving interest and competence from the clinician, R.J. and his mother are open to developing a relationship and hoping to build mutual trust. Thus, they are forthright regarding what they have and have not done and R.J. explains what the mindfulness intervention does and does not accomplish. The mother brings a sealed envelope from R.J.'s teachers. By listening and displaying empathy during and after the first encounter, the clinician and her team provided building blocks to a more trusting health

Table 1. Illustrating How the Learning Loop Model (LLM) Enhances Standard SDM Models Using the Use Case

	Standard SDM Models	Additions From LLM
Research question	Is the SDM intervention associated with: • Better outcomes? • More satisfaction with the processes of care? • More satisfaction with outcomes? • Less regret over decisions?	Do outcomes differ when intervention modules are delivered at first visits, rather than to patients who have been with the practice for 2 years or more. In which population is SDM associated with: • Better outcomes • Greater satisfaction with the process • Greater satisfaction with outcomes • Less regret Are the outcomes moderated or mediated by: • Trust • Length and stability of clinical relationship • Stability of health care provider team • Concordance or discordance between parent and child regarding nature of preferences
Constructs of interest	Participant demographics (age, sex, comorbid conditions) Clinician context Decision scenario Adherence	Family context Competing priorities Emotional context Stability, consistency, and trust associated with the relationship Unexpected previous outcomes
Population studied/ unit of analysis	Patient	Clinician–family dyad (patient, family, extended care team [teachers, nurses, therapists], clinician, and clinical team)
Nuances in interpretation		Assessing the extent to which SDM has different impacts in patients with: • a history of fragmented care or adversarial interactions with health care team • Patients with longstanding trusting relationships • Children and parents who are more aligned in their choices • Patients with better outcomes in the past • Patients who have not experienced an unhappy unexpected outcome Are the aforementioned factors related to different distributions of health care choices in otherwise-similar circumstances? Is the impact of SDM on the distribution of decisions different based on the aforementioned factors?

SDM indicates shared decision making.

care relationship than R.J.'s mother had previously experienced. The more relational tone of this interaction allows R.J.'s mother feel safe to articulate the constraints of her work schedule and transportation barriers that impeded pursuit of counseling. With the information from the health educator and school in hand, the clinician confirms a diagnosis of ADHD, and engages in dialogue with R.J. and his mother about the condition, options, and expected outcomes for treatment. After this exchange of information, R.J. volunteers he feels more agitated on days he uses his rescue inhaler. This new information initiates further dialogue in which the clinician explains and explores possible connection between inhaler side effects and R.J.'s behavior. They adjust the care plan to step up R.J.'s asthma therapy to preventive inhaled corticosteroids, opt to pursue school-based counseling services only, and plan for follow-up by phone in 1 week. Future loops through the model over time help to build trusting relationships that qualitatively change how both family and clinician respond to one another in a way that promotes adherence and reduces in-person use of health care services. The trust is maintained so long as each party both honors it and maintains open lines for dialogue.

Consider the implications of R.J. as an exemplar subject in a study of patient-centered care for children with asthma. Researchers are interested in understanding correlates of success to prepare for a planned clinical trial. Applying the LLM might prompt researchers to assess the contributions of context, conditions, individuals, and their interactions beyond distinct decision making processes when studying implementation and outcomes. LLM could assist researchers by helping to suggest additional lines of inquiry, by serving as a checklist for thinking about inclusion of constructs and selection of participants, and by aiding in the interpretation of findings, especially by recognizing centrality of continuity, relationships, and trust for the experience and conduct of care and its implications for adherence. Table 1 illustrates how application of the LLM might enhance the research team's considerations regarding these domains.

DISCUSSION

Evolving relationship dynamics between the clinician and the family (including elements of trust, empathy, and attunement[38]) are underemphasized in practice yet represent key contextual variables that can impact both the

process and outcomes of SDM, especially in the context of chronic conditions. If it is the process of SDM (rather than the construction of any number of decision-specific algorithms) that is the key to its widespread adoption,[22] then understanding the central importance of the relationships driving that process over time may be essential to more consistent implementation of SDM in pediatric settings. One implication is that the relationships (and things that promote positive relationships) may be key targets for interventions to improve care.

The LLM provides guidance for researching the outcomes of iterative decision-making in chronic illness. It suggests the importance of considering how the relationship between family and clinician may be impacted by process of decision-making, the negotiation of facts, and the identification of meaning. Further, beyond SDM's recognition of the ethical requirement to incorporate the agency of the family, the LLM suggests that the development of the index child within the family creates its own pragmatic and ethical considerations when considering agency and relationships both. Attending to these aspects may allow the clinician to develop more nimble and responsive relationships.

The explicit prioritization of relationships, its correlates (eg, continuity, duration, trust), and their impacts is a novelty and strength of the LLM. Clinicians are not widgets, and neither are patients. Excellent care of chronic illness plays out over time. The model supports asking whether there are differences in outcomes of collaborative decision-making in settings with greater degree of continuity between patient/family and their identified personal doctor or nurse, as compared with those settings in which the care team is more diffuse. The LLM provides guidance to help researchers distinguish questions of access from those of continuity and may help to explain why and how clinicians caring for underserved children with special health care needs are less likely to engage in SDM.[15] The model can help researchers identify which barriers to SDM are at play in specific settings. It has been shown that "physicians primarily derive professional satisfaction from relationships with patients."[50] By highlighting relationships, the LLM implies that experiential learning and relationship-building gained from the process of SDM may motivate clinicians and their teams to reframe shared decision making not as a checkbox to complete but as a core strategy to deliver better care, promote clinician and patient satisfaction, and combat burnout.

The LLM draws attention to the substantial work required of patients and families between clinical encounters. Such attention may suggest opportunities to reduce the burden of implementing a care plan, especially when multiple conditions are involved. Rather than an episodic exercise to be recalibrated in response to an acute clinical setback, the model implies that there are many currently unattended opportunities to build relationships by engaging around the care plan between encounters. Developing systems that allow meaningful information to be shared with clinicians and other partners on the health care team in closer approximation to real time may allow families to shorten learning loops and the health care system to reduce the burden of caregiving. By narrowing the interval between decision-outcome-next decision, families may be able to enhance the quality of their decisions, improve their ability to adhere to the care plan, and improve children's clinical outcomes.

CONCLUSIONS

The LLM highlights the dynamic iterative nature of exchanges among the clinical team, patient, and family. It explicitly recognizes that the relationship between clinician and family is central to each decision-making cycle and a modifier and moderator of health care. LLM incorporates critical practice, family, experiential, and emotional variables that influence decision-making at and between clinic visits including adherence. The LLM suggests that better collaboration can improve care planning, build relationships, and improve outcomes for children with special health care needs. These relationships are infrastructure in the form of human capital and may buffer negative impacts of unexpected and undesirable clinical outcomes. The model highlights the importance of continuity to relationships, suggests the importance of researchers developing and applying metrics related to clinician−family relationships, and its association with decision-making. Such metrics should capture and be robust to development of relationships over time.

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