

Intergenerational Decision Making: The Role of Family Relationships in Medical Decision Making

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Abstract

A symposium held at the 42nd annual Society for Medical Decision Making conference on October 26, 2020, focused on intergenerational decision making. The symposium covered existing research and clinical experiences using formal presentations and moderated discussion and was attended by 43 people. Presentations focused on the roles of pediatric patients in decision making, caregiver decision making for a child with complex medical needs, caregiver involvement in advanced care planning, and the inclusion of spillover effects in economic evaluations. The moderated discussion, summarized in this article, highlighted existing resources and gaps in intergenerational decision making in four areas: decision aids, economic evaluation, participant perspectives, and measures. Intergenerational decision making is an understudied and poorly understood aspect of medical decision making that requires particular attention as our society ages and technological advances provide new innovations for life-sustaining measures across all stages of the lifespan.

Keywords

advance care planning, children with special health care needs, end of life, shared decision making, spillover effects

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Introduction

The 2001 Institute of Medicine report, “Crossing the Quality Chasm: A New Health System for the 21st Century,” recommendation that shared decision making and communication between health care providers and patients could improve care quality resulted in exponential growth of medical decision making as a research topic.¹ Traditionally, shared decision-making research focuses on decision making between adult patients and their providers. Similarly, outcomes research—including cost-effectiveness analysis—focuses on individual patients’ outcomes. In reality, medical decisions often involve intergenerational family members not only through their role in the decision-making process, but also through the downstream effects from the decisions, such as future caregiving needs as well as family members’ own health and emotional well-being. Intergenerational relationships between patients and their family members play an essential and

complex role in medical decision making. However, most research focuses on a decision dyad—namely a health care provider and an adult patient who is cognitively able to participate in decision making and outcomes specific to the patient and at most a primary caregiver.²

A symposium held at the 42nd annual meeting of the Society for Medical Decision Making on October 26, 2020, highlighted challenges and opportunities when considering intergenerational aspects of medical decision making in research, evaluation, and clinical practice. The symposium was organized by the Decision Sciences for Child Health Collaborative, the Society for Medical Decision Making’s pediatric interest group. A panel of experts in medical decision making and clinical practice

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in pediatrics and palliative care presented their experiences in the field: Ellen Lipstein, MD, MPH, a general pediatrician at Cincinnati Children's Hospital Medical Center and an Associate Professor in the Department of Pediatrics at the University of Cincinnati College of Medicine; Robert and Gari Lyn Lundstrom, parents of an adult child with chronic illness; Djin Tay, PhD, RN, then a postdoctoral fellow at the College of Nursing at the University of Utah; and Eve Wittenberg, PhD, a Senior Research Scientist at the Harvard T.H. Chan School of Public Health. Saadia Sediqzadah, MD, SM, psychiatrist at St. Michael's Hospital in Toronto, Canada, and a lecturer in the Department of Psychiatry at the University of Toronto moderated the symposium. Each presenter shared a state-of-the-art overview of their field, and the session concluded with a panel discussion of parallels across topics, critical gaps, and future directions.

This article summarizes the presentations at the symposium and offers recommendations for how intergenerational decision making could be supported in clinical practice and investigated in research.

Pediatric Decision Making for Patients and Their Parents (Presented by Ellen Lipstein)

In pediatrics, shared decision making involves, at a minimum, a triad of the health care provider, parent or guardian (hereafter parent), and the patient.³ Despite this, most work in pediatric shared decision making focuses on the health care provider–parent dyad, with

little attention to the role of the patient. This focus risks underrecognizing both the capabilities of pediatric patients to engage with health care providers and the “clinically unseen” medical decision-making interactions that occur between parents and their children. The complexity of decision making within a triad likely contributes to the limited studies addressing it.

Pediatric medical decision making is a skill that needs to be fostered for all members of the triad. For children this means finding a developmentally appropriate role for them in decision making. For children with more limited skills, this may mean something as basic as expressing a preference for the place in the house where they take medication. As children mature, their decision-making role grows to include learning how to report their own symptoms, express preferences, and ask questions. By gradually increasing the child's role, the child develops the skills necessary for eventually transitioning to the adult care setting where they will be the patient in a more traditional decision-making dyad.^{4,5}

Like adults, adolescents have differing preferences regarding the amount of control they have in significant medical decisions, but most do want a role.^{6,7} Similarly, the roles they ascribe to themselves, their parents, and their health care providers may be specific to the decision. For example, in a qualitative study of adolescents who had participated in treatment decisions for their chronic condition, adolescents described their role as reporting symptoms, discussing preferences, and participating in decision making.⁷ However, in a similar study of transgender and gender-diverse adolescents considering treatment with gender-affirming hormones, adolescents described their role as researching treatment options and being a primary decision maker.⁸ Studies that involve the parents of the same adolescents discussed above highlight that an additional challenge is parents' and adolescents' differing perspectives on the roles each has in decision making, as well as the roles they want themselves and the other members of the decision-making team to have.^{8,9} While many of these challenges are similar to those faced in a traditional patient–provider decision dyad, many aspects of the decision making and related struggle faced by adolescents may be unobserved or unrecognized by the health care provider as they may occur outside the clinical setting.¹⁰

The limited research on pediatric shared decision making scratches the surface of understanding the complexities of the decision triad, how decision roles evolve in parallel to a child's development, and how to integrate disparate perspectives. There are both research and

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practical challenges that must be addressed to move the field forward. Practically speaking, how should clinicians and families weigh differing goals and preferences between parents and pediatric patients? What design and informational elements are required to develop decision aids that engage both parents and pediatric patients? Finally, perhaps the largest research challenge is that of measurement. No measures are designed to focus on the provider–parent–pediatric patient triad and virtually none are validated for use by parents or pediatric patients.

Parental Experiences in Decision Making for a Child With Special Needs (Presented by Robert and Gari Lyn Lundstrom)

As the parents of a 24-year-old child that is nonverbal and non-weight bearing, we have learned a few lessons about medical decision making. First, we now recognize the decision-making process as a balancing of risks, benefits, and quality of life. Second, we have guiding principles for decision making that have helped us make medical decisions through wildly varying situations. Third, we have learned that we are not alone in the decision-making process. These hard-learned lessons taught us to be fluid and flexible in decision making to meet the challenges and joys of parenting a child with special needs.

Balancing Risks and Benefits

Our priorities for care have changed as our son has grown older and new information has become available to us. These priorities center on balancing and rebalancing risks and benefits to his quality of life. Our initial diagnosis suggested our son would continue to develop and improve as he grew older, so we framed our decisions for medical intervention as only temporary. At the chronological age of 8 but the developmental age of 4 months, and with new diagnostic testing, his diagnosis changed to a progressive degenerative disease from which he would not recover. Thus, what we previously thought of as temporary interventions became permanent, and our priority in medical decisions began to shift from short-term relief to long-term safety and comfort.

Guiding Principles

Our guiding principles became maintaining independence for as long as possible and optimizing his quality of life. When faced with medical decisions, we ask ourselves the

following: 1) Does this procedure or intervention have to be done right now? 2) Are there sufficient long-term benefits to protecting, preserving, or improving quality of life to justify this procedure or intervention? This second question is often difficult to answer since we do not have an affirmative method of communication with our son. For us, our son's smile and laugh are our indicators for his quality of life. When they disappear, we know we are witnessing a decline in quality of life.

Another guiding principle that has informed our decisions over the years is embedded within our faith. A tenet in the doctrine of the Church of Jesus Christ of Latter day Saints teaches that "all the minds and spirits that God ever sent into the world are susceptible of enlargement." For our son, we seek to make decisions that not only maintain his quality of life but also provide him the opportunity to grow while in this life. With every decision we make, there is much prayer and reflection on this principle.

We Are Not Alone

Decisions involving quality of life are the most difficult for us to make because they usually involve considerable unknowns. For this reason, we tend to seek as much advice as possible, including from health care providers, family members, religious leaders, and our other children. For example, we had delayed placing a tracheostomy for many years in hopes of preserving our son's independence. Unfortunately, just before he turned 18, he suddenly developed pneumonia at home that resulted in a dramatic drop in oxygen levels and caused his heart to stop. He ended up intubated in a pediatric intensive care unit (PICU). Surprisingly, with tube in his throat and his airway secure, he started smiling and laughing again. We surmised that he had been working so hard on breathing, to the detriment of smiling and interpersonal interaction. With this immediate improvement in his quality of life, we believed it was time for a tracheostomy, but we feared that his doctors would advise against the procedure.

After about 2 weeks in the PICU, we asked for a care conference with his entire health care team. We expressed our desire to pursue a tracheostomy, which was met with great relief from all his doctors. In response, we felt great relief knowing that we were not alone in this decision. Time and time again, we realize that we can rely on our health care providers as partners in decision making.

However, the tracheostomy did have its consequences. We went from a "3 to 4 hours a day kid" to a "20 hours a day kid," and this level of care has affected our other

children. Although our decision to place the tracheostomy would not change, our approach may have. We learned how important it is to involve others who will be affected by our medical decisions, to both prepare them mentally and practically for their own new life changes.

Twenty-Four Years of Decisions

In 24 years of making medical decisions for our son, we made a lot of mistakes and learned a lot of lessons. Our decision-making paradigm that balances *independence*, *quality of life*, and *our faith* works for us (most of the time). It is flexible enough to evolve and adapt to new information and circumstances. This approach has served us well so far and, hopefully, will provide some stability in the difficult decisions ahead.

Advanced Care Planning for Chronically Ill Adults and Their Caregivers (Presented by Djin Tay)

Advance care planning (ACP) is a process of making future decisions for medical care in critical illness if one is no longer able to speak for oneself. ACP encompasses the reflection upon, and communication of one's end of life values, goals, preferences for medical treatments in serious illness.¹¹ Patients who have documented their wishes in directives may receive more preference concordant care, have higher quality end of life care, and lower odds of hospital death.^{12–15} Many dyadic ACP interventions default to a patient-centric model of decision making, overlooking the highly engaged role that some caregivers, such as spouses and adult children, take in shared decision making.

However, involving families in the ACP process is increasingly being advocated for.^{16,17} The earliest dyadic ACP intervention was the Family/Adolescent-Centered (FACE) intervention for adolescents with HIV.¹⁸ In adults, the earliest family-centric dyadic ACP interventions was the Sharing Patients' Illness Representations to Increase Trust (SPIRIT) intervention for patients with end-stage renal disease.¹⁹ Both interventions largely focused on clarification of patient values within a patient education framework. In RCTs across a wide range of populations from adolescent cancer, adult HIV, heart failure, and dementia patient, both interventions demonstrated efficacy in improved dyadic understanding and concordance of preferences, confidence in decision making, anxiety and depression among caregivers, and decisional conflict.^{20–27} More recent dyadic ACP models primarily focused on the emotional and collaborative

aspects of shared decisions by reducing emotional reactivity with mindfulness stress-reduction techniques; promoting improved consensus by having dyads complete advanced directives separately, then together; and emphasizing collaborative coping.^{28–31} While these more recent models demonstrated preliminary efficacy in reducing decisional conflict, improving preference concordance, and lowering distress over time, they are largely limited by smaller sample sizes and the lack of a control group.

One group of patients for whom ACP may be particularly important, yet underutilized, is home health patients. However, very few dyadic interventions have been specifically developed for the home health patient and caregiver population.^{26,30–33} Home health patients tend to be older, have more comorbidities and functional limitations, and experience greater inpatient and emergency department care utilization than other long-term care patient populations.^{34–37} Yet compared with long-term care users in nursing homes and hospice, home health patients have a lower rate of advance care planning, leaving family members and other stakeholders to negotiate a care plan among themselves without clear guidance.³⁶

There is a need to acknowledge the relational aspects of patient-caregiver decision making for end-of-life decisions, such as the recognition that decisions can be influenced by others, and acknowledgement for the potential of ethical dilemmas when dyads disagree, or experience an unequal distribution of power such as in controlling or conflictual relationships, which can affect the quality of communication and decision making.^{38,39} Collaborative decision making can provide benefits for patients and caregivers such as reduction of decisional conflict, and improvement in decision concordance.^{26,30,31} Additionally, power dynamics of decision making may shift when a member of the dyad who had typically been in a dominant decision-making role, assumes the patient role and becomes more dependent on the caregiver for decisional support, such as an adult child. Caregivers may require additional support in these new roles—when caregivers are tasked to take on decision making on behalf of cognitively impaired patients, the literature support that it is common for caregivers to be underprepared and face emotional burdens in surrogate decision making.⁴⁰

Decisional quality for end-of-life shared decisions is limited and is often assessed by examining decision-making concordance between end-of-life treatments and other medical treatments.^{41,42} Concordance refers to the degree of accuracy that a surrogate decision maker is able to predict the preferences of a patient for end-of-life

care, and has been described as the ideal outcome of shared decision making.⁴³ The assessment of communication quality or perceived decisional conflict may also be useful. However, surrogate decision makers may face complex decisions outside of the limited scope of treatments listed in advance directives or living wills. Thus, aside from examining preferences for life-sustaining treatments, there may be utility for dyadic measures that assess concordance between patients and their caregivers in wider end-of-life values, such as the quality of death and dying.⁴⁴ Alternatively, the concept of concordance can be studied by examining convergent and divergent interactions in qualitative data using observational methods, which is also underutilized.⁴⁵

Spillover Effects in Medical Decision Making (Presented by Eve Wittenberg)

Recognition of both the existence and importance of intergenerational contributions to decision making requires consideration of individuals beyond the patient in evaluations of interventions and treatments. This includes in the described measures of decision quality, as well as in economic evaluations that quantify the impact of a disease on health care costs and outcomes. Family members are often affected by an individual patient's illness in addition to being involved in decision making. "Spillover effects" are the measurable effects of a patient's illness on surrounding individuals, including the patient's caregivers, their family members, and sometimes also unrelated household members. The inclusion of spillover effects in economic evaluation more accurately depicts the entirety of both costs and outcomes that ensue from an intervention or treatment, compared with more traditional frameworks that focus exclusively on the "patient." Their inclusion has been endorsed by guiding bodies in many countries including the United States' 2nd Panel on Cost Effectiveness in Health and Medicine.⁴⁶

There are two mechanisms that explain spillover: "caring for" and "caring about" an individual who is ill. Caring for is the literal caretaking of an individual, meaning providing medical care, emotional and psychological care, managing finances and health care services, providing feeding and bathing, and so on, on an informal basis (meaning unpaid). Caring about is the emotional connection or feelings resulting from having a family member who is ill, excluding actual caretaking tasks. Both can result in physical and emotional effects for the family member or caregiver, such as physical

conditions of pain, fatigue, and headache, and emotional and psychological conditions such as anxiety, depression, and stress. Increasing attention has been paid to non-health related effects on caregivers, such as financial burden, loss of social interaction, employment effects (job loss, reduced hours, early retirement), and educational losses (lower achievement, delayed entry).⁴⁷

While research on methods for measurement and incorporation of spillover effects in economic evaluation continue to advance, approaches can be broadly categorized into those that capture health-related quality of life, for estimation of quality adjusted life years (QALYs), and those that capture the slightly broader concept of care-related quality of life, which includes health as well as dimensions that are specific to the caregiving role, such as fulfillment, relationships, and finances.⁴⁸ Preference-based indexes for care-related quality of life have been estimated yet are of a different underlying scale from QALYs so can only be used independently in evaluations—not in combination with QALYs.⁴⁹

Clinical care and research exist in parallel spheres, and as each adjusts to greater recognition of the role of families in health and health care, the other responds in kind. Consideration of spillover effects is the evaluation-relevant companion to intergenerational decision making in a clinical context. As families' roles are more broadly recognized and encouraged, to the benefit of patients and family members alike, the entire picture of health and health care expands and more accurately reflects the reality of decision making and care outcomes.

Moderated Discussion

As highlighted in this symposium, current approaches for considering intergenerational decision making in clinical care and research are inadequate. Medical decision making may happen differently than other decision making (e.g., financial) within a household. By clarifying health-related values early using structured tools and methods, health care decisions can be improved. We must think about how we balance decision-making roles among key stakeholders—patients, providers, family members, and caregivers. The complex relationships between stakeholders challenges our assumptions about whose preferences, needs, and values should be prioritized. To inform this question, we need to identify tools to measure relationships within intergenerational decision making networks that include patients, family members, and caregivers with a wide variety of ages and relationships (e.g., parent/younger child, adult child/parent, siblings, etc.).^{8,9}

Decision Aids

Our four presentations discuss decision making but did not address how to improve decision making. A frequently used approach to facilitate shared decision making is the use of patient decision aids.⁵⁰ The majority of such tools are designed for dyadic decision making, between an adult patient and a health care provider, but some approaches more easily incorporate multiple decision makers. For example, conversation aids can be used to engage multiple participants in the decision during a health care encounter.^{51–54} For decisions without an existing tool, the Ottawa Personal Decision Guide for Two (<https://decisionaid.ohri.ca/docs/das/OPDGx2.pdf>) may be useful. However, more tools designed specifically for intergenerational decision making need to be developed and rigorously evaluated.

Economic Evaluation

Within the field of economic evaluation, empirical research on intergenerational decision making is needed to inform how non-patient utilities are incorporated into economic evaluations. While few studies exist on intergenerational decision making, several studies have used empirical data to evaluate outcomes that result from illness among spouses and between parents and their children. One study found that widows and widowers delay and forgo health care after the death of a spouse while another found lung health, a marker of overall health, to be similar between spouses.^{55–57} In pediatrics, giving birth to a child with congenital anomalies was associated with increased risk of premature cardiovascular disease and earlier maternal death.⁵⁸ When an adult child has a parent who newly requires long-term care, the child provides increased emotional, financial, and household help, as well as personal care supports to their parents.⁵⁹ The likelihood of providing support is correlated with the parents providing reciprocal support such as paying for their child's help. Potential data sources for future studies include the Utah Population Database, the Panel Study of Income Dynamics, and the National Longitudinal Study of Adolescent to Adult Health, which support the study of health and healthcare utilization within families and across generations.^{60–62}

While economic evaluations could weight a caregiver's utility equally to the patient, in reality often multiple caregivers are involved in the decision, such as a two-parent household caring for an ill child or multiple children caring for an aging parent. The addition of multiple caregivers to an economic model could potentially

outweigh the patient's utility, leading to a perverse outcome in which patients' needs are dominated by families'. Moreover, in clinical practice, the weight of a caregiver's opinion differs based on the decision and setting. For example, in adult end-of-life care, ethical principles require that the patient's opinion carries the most weight.^{63,64} Overall, explicitly measuring the preferences for weighing of patient, caregiver, and family member outcomes/utilities could inform weights in economic evaluations and bring evaluations closer to real-world practice.

Understanding Perspectives in Intergenerational Decision Making

On the qualitative side, several approaches can be used to include intergenerational perspectives. Researchers and clinicians must know who is part of the decision-making team. One method for determining this is to ask patients or parents to draw a pie chart showing the distribution of decisional responsibility among all participants.^{8,9} Another approach is to use snowball sampling, in which the researcher asks an interview participant to connect them to other participants in the decision.⁶⁵ With either of these approaches some stakeholders may still go unrecognized, and therefore their role and outcomes unacknowledged. Using an ethnographic approach may allow for near complete capture of all decision stakeholders.

A qualitative approach may also help explore newer and shifting dynamics in families. For example, with a rise in late-in-life divorces, hearing from those with experience can shed light on how they have reconfigured previously established family dynamics that formerly dictated the roles adult children and former spouses play in medical decision making at end of life.^{66,67} Similarly, shifts in demographics in the United States, particularly among Asian and Hispanic populations, has resulted in a growing prevalence of cultures with multigenerational households, and this trend has continued to rise despite the end of the Great Recession.⁶⁸ One can imagine, given dependent care needs within these families, that the rising prevalence of multigenerational households could result in a greater need for understanding intergenerational decision making in health through qualitative studies.

Measures

One of the key limitations to advancing the field of intergenerational decision making is the lack of measures. Measures for quantifying spillover effects in economic


terms (as economic “preferences”) are advancing, but limitations remain in terms of the adoption of measures, the suitability across contexts, and the value of these measures in models and practice. Few measures can be applied across all age groups. Only recently was the first pediatric and young adult health utility value set completed.⁶⁹ Most measures of decision making target an individual stakeholder and at most include the adult patient–provider dyad, such as in measures of decisional responsibility, shared decision making, decisional conflict, stakeholder utility, and independence. Few measures evaluate child–parent and triadic decision making.^{70,71} Future measures could include evaluating group decisional quality rather than individual decisional quality. Measures should also include recommendations on age and developmental appropriateness given the differences across age groups for health-related quality of life. Measures may have clinical utility by guiding and improving the decision-making process, and whether a measure can be used to improve clinical practice may be more important than whether a measure has ideal psychometric properties.


Conclusion

Knowledge is limited on intergenerational decision making both in practice and research. Future directions should explore the reality of intergenerational decision making in clinical practice using qualitative and quantitative data and should pursue the development of new tools and approaches to assess and integrate family members and caregivers across generations into decision science. Particular attention should be paid to how intergenerational decision making differs between upward (adult children caring for parents) and downward (parents caring for children) decision making. Funders should prioritize studies that develop new intergenerational cohorts and encourage existing cohort studies to collect ancillary data to enhance our understanding of how to improve intergenerational decision making in practice, research, and policy.

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