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Parent perspectives in shared decision-making for children with medical complexity

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Abstract

Objective: Shared decision-making (SDM) may improve outcomes for children with medical complexity (CMC). CMC have lower rates of SDM than other children, but little is known about how to improve SDM for CMC. The objective of this study is to describe parent perspectives of

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SDM for CMC and identify opportunities to improve elements of SDM specific to this vulnerable population.

Methods: Interviews with parents of CMC explored SDM preferences and experiences. Eligible parents were 18 years old, English- or Spanish-speaking, with a CMC < 12 years old. Interviews were recorded, transcribed, and analyzed by independent coders for shared themes using modified grounded theory. Codes were developed using an iterative process, beginning with open-coding of a subset of transcripts followed by discussion with all team members, and distillation into preliminary codes. Subsequent coding reviews were conducted until no new themes emerged and existing themes were fully explored.

Results: We conducted interviews with 32 parents (27 in English, mean parent age 34 years, SD=7; mean child age 4 years, SD=4; 50% with household income <\$50,000, 47% with low health literacy) in inpatient and outpatient settings. Three categories of themes emerged: participant, knowledge, and context. Key opportunities to improve SDM included: providing a shared decision timeline, purposefully integrating patient preferences and values, and addressing uncertainty in decisions.

Conclusion: Our results provide insight into parent experiences with SDM for CMC. We identified unique opportunities to improve SDM for CMC that will inform future research and interventions to improve SDM for CMC.

What's New: We described parent experiences in shared decision-making for children with medical complexity using parent interviews. Facilitators of shared decision-making included establishing a shared decision timeline, eliciting child preferences and values, and addressing uncertainties in decisions.

Keywords

children with special health care needs; family-centered care; qualitative research

Introduction

Shared decision-making (SDM), a key component for improving care quality for patients with chronic illnesses, is a collaborative communication process to reach treatment plan agreement while valuing both the family's goals and the clinician's expertise.^{1,2} SDM is associated with decreased disease severity or improved outcomes in asthma, attention deficit hyperactivity disorder, and diabetes.³⁻⁶ The American Academy of Pediatrics endorsed SDM as a promising tool to improve health outcomes for children with chronic conditions.⁷

Children with medical complexity (CMC) have chronic conditions that result in high service needs, high resource use, and severe functional disability.⁸ CMC have overall poorer quality SDM than children without medical complexity.⁹ One contributing factor to poor quality SDM may be that CMC have multiple comorbid conditions that make treatment outcomes difficult to predict.¹⁰ Decisions with no clear best option should be guided by an individual's preferences and values through SDM.¹¹

To effectively improve SDM for CMC, we must understand how SDM fits within the complex care system families of CMC navigate. Prior SDM research primarily focuses on

decision aids for discrete medical conditions in individuals without medical complexity.¹² In geriatric medicine, there is growing recognition that SDM for individuals with multiple comorbidities should be more holistic and integrate patients' overall goals of care, preferences, and values.¹³⁻¹⁵ For adults with medical complexity, the Chronic Care Model is commonly used to guide systems level interventions (e.g. policy change, self-management support, and clinical information systems) that facilitate productive interactions between patients and providers, resulting in improved health outcomes.¹⁶ The Chronic Care Model has been adapted to pediatric chronic illness and proposed for the care of CMC.¹⁷⁻²¹ While SDM may facilitate productive interactions among patients, caregivers, and providers, the Chronic Care Model for CMC has not formally incorporated SDM.

Little is known about how to improve SDM for CMC.^{22,23} Thus, we aimed to identify components of SDM unique to the care of CMC.^{23,24} Specifically, from the perspective of parents, we sought to describe SDM for CMC, understand SDM in the context of the Chronic Care Model, and identify opportunities to improve SDM for CMC in clinical practice.

Methods:

We conducted a single-institution qualitative study that applied modified grounded theory methodology to semi-structured, individual interviews with adult caregivers (parents) of CMC. Between October 19, 2016 and September 8, 2017, we recruited parents of CMC who received inpatient care on the hospital medicine service at Lucile Packard Children's Hospital Stanford or ambulatory care at Stanford Children's Complex Primary Care Clinic.²⁵

Eligibility criteria included parents ≥ 18 years, English- or Spanish-speaking, child <12 years and with medical complexity. While most CMC rely on parents as lifelong decisionmakers, some do not. We did not want to presume which children ≥ 12 years had some capacity for decision-making.²⁶ Thus we applied age inclusion conventions from similar studies in non-CMC populations. We defined medical complexity as meeting all of the following criteria in the past 12 months: ambulatory visits with at least two subspecialty providers, functional impairment due to a chronic condition, and either one admission to an intensive care unit or two non-elective admissions to the acute care floor. There is currently no established method to prospectively identify CMC, so we retrospectively confirmed medical complexity using previously described criteria of parents' responses to the Children with Special Health Care Needs Screener and utilization of subspecialty and hospital services.²⁷ We excluded parents known by the primary medical team to have cognitive or mental health disorders to prevent inclusion of those who may not be able to provide informed consent. We used purposive sampling of gender and race/ethnicity to obtain perspectives reflective of the local population. This study was embedded in a funded study to develop goal-centered care plans. Due to time constraints of provider participants in the larger study, we were unable to include provider interviews in this work.

The initial interview guide contained open-ended questions about: 1) parental experiences in making health decisions for their child, 2) participants in decision-making, 3) timescale for

decision-making, and 4) perceived value of information gathered during decision-making. We used modified grounded theory to develop initial interview questions informed by current literature rather than completely open-ended questions.^{23,28-30} The interview guide was revised iteratively by several team members (JLL, PNB, BHF, SAH, OA, LMS) to explore newly uncovered topics and probe more deeply into existing topics until thematic saturation was achieved. Two post-baccalaureate research assistants underwent 25 hours of training in qualitative interviewing conducted by LMS, JLL, and PNB. We conducted interviews in English or Spanish, in outpatient clinic rooms, inpatient hospital rooms, or hospital conference rooms, per parent preference. A research assistant with native Spanish language proficiency conducted Spanish interviews. Interviews in ambulatory care occurred immediately after clinic visits. Interviews in inpatient care occurred at least 24 hours after admission.

Participants completed post-interview surveys of sociodemographics, child medical history, health literacy, and overall SDM quality in the past year. We measured health literacy with the Newest Vital Sign.³¹ We assessed quality of SDM using the SDM domain of the National Survey of Children With Special Health Care Needs 2009-2010.³² Each participant received a \$50 gift card for participation.

Analysis

Each interview lasted 45-60 minutes, was audio-recorded, and was transcribed with personal identifiers removed. A certified medical Spanish interpreter translated Spanish transcripts into English. Independent coders (JLL, CLC, SAH, LMS), from different health disciplines with varied knowledge of SDM and clinical care for CMC, analyzed each transcript using modified grounded theory.²⁸ Modified grounded theory differs from classic grounded theory mainly by forming concepts from the researcher's interpretations rather than word-by-word data coding.³³ We developed codes through an iterative, multi-step process, beginning with open-coding of the first subset of transcripts. These initial codes were discussed with all team members and distilled into fifteen codes. Two coders (JLL, CLC) independently applied the codes to all transcripts, identifying an additional eight codes. Serial coding reviews and team discussions continued until themes were fully explored and no new themes emerged. Subsequent team discussions applied the results to the Chronic Care Model and identified opportunities to improve SDM.³⁰ We documented coding reviews and themes in Dedoose and Microsoft® Excel®.³⁴ The Stanford University Institutional Review Board approved the study protocol. All participants provided informed consent.

Results:

Of the 41 eligible parents approached, 32 (78%) agreed to participate in the interview. Primary reasons for declining participation were time constraints and childcare needs. Participants' median age was 33 years (range 20-55), 84% female, 56% Hispanic, and 47% had low health literacy. Children of participants had a median age of 3 years (range 1-11), 56% male, 75% technology dependent, and 47% with neurodevelopmental delay. Parent and child characteristics detailed in Table 1 and Table 2 online, respectively. We include limited

quotes illustrating themes throughout the body of the manuscript with additional quotes in Table 3 online.

We identified 241 total distinct decisions. Recurring categories for decisions included pain management, development, illness prevention, medication changes, and medical procedures. Pain management primarily focused on baseline pain from a child's underlying condition. Development included selecting schools and securing assistive learning equipment or therapies. Illness prevention overwhelmingly concerned avoiding hospitalization. Almost every interview mentioned medication changes and procedures. While clinically some decisions like medication changes seem less well-suited for SDM, parents identified all of these decisions as important, collaborative decisions with the medical team.

Thematic discoveries

Themes fit into three topical categories: *participant*, *knowledge*, and *context*. The participant category related to the persons involved in decision-making. The knowledge category included informational-based factors that parents valued in decision-making. The context category included environmental or background factors that affected parents' decision-making.

Participant Theme 1: The patient's role in decision-making primarily centers on clinical outcomes while patient preferences are readily attainable but underutilized.

Patient preferences and values such as liking or disliking an activity (e.g., enjoying going to the park, refusing to participate in feeding exercises with the occupational therapist) were rarely mentioned as key factors in decision-making. Patient factors that were frequently discussed pertained to child's current state of health (e.g. sick, hospitalized, healthy), test results, and prior clinical outcomes from medical decisions (e.g. previous surgery resulting in prolonged hospitalization). In spite of the prevalence of neurodevelopmental delay in their children, parents consistently identified behavioral cues to the patients' preferences. Strikingly, there were almost no descriptions of providers asking families about patient preferences.

Participant Theme 2: Parents overall felt they should be in control of decision-making

All parents felt they were the ultimate decision maker for their child. Even when parents appeared to defer decisions to providers when the parents felt the decision was too technical (e.g., medication dosing), they still felt in control of the decision. "And then [I] let the doctors know, "Okay, we're seeing a lot of growth... You may want to look at the med doses, and make sure they're appropriate for the size." -*Parent 443, age 33, some college, child age 7 months*. A number of factors hindered SDM, often resulting in the parent acting as sole decision-maker, as described in Table 3. Strong emotions and beliefs, including fear about treatment options, at times superseded other decision-making factors. In some non-life-threatening situations, parental convenience drove a decision, with parents articulating that providers did not understand their lived experience.

Participant Theme 3: Providers determine the urgency of the decision and reallocate decision ownership.

Some elements of decision-making were perceived by parents to be driven primarily by providers: (1) the urgency of the decision and (2) assignment of decision ownership. In circumstances in which providers said procedures “had” to be done to prevent death or other lifelong consequences, parents felt they had no role in decision-making because they lacked medical expertise. In contrast, providers explicitly deferred end-of-life decisions during their child’s critical illness to parents, and parents felt very “in control,” often choosing to make these decisions with close friends and family without providers. However, providers remained key informants for identifying when end-of-life discussions needed to occur.

Knowledge factor 1: The source of information affects the influence that information has on the decision.

Often, non-professional sources of information were more influential than the child’s health care team. One parent wavered in her decision to give her child attention deficit hyperactivity disorder medication for months before a news report finally made her feel comfortable with the providers’ recommendations. “I just watched a report on Fox News on the lady from England...who said that children through adolescent and teenage years, if they took ADHD and ADD medication...made better choices and did better overall...That gives me hope.” -*Parent 498, parent and child age missing, some college*. Parents valued information from parent support groups, social media, and local parent mentorship teams, attributing many decisions to hearing other parents’ experiences. Parents viewed providers with conflicting recommendations as different sources of information rather than a challenge to SDM.

Knowledge factor 2: Greater parent knowledge and experience helped parents play a more active role in decisions.

Greater parental knowledge and experience empowered parents to articulate their concerns and actively participate in decision-making. Parent knowledge included expertise about their child and the risks or benefits of treatment options. For example, one parent’s knowledge of the progressive nature of her child’s seizure disorder shifted her care priorities. “I kind of stopped thinking about ‘how can we get these seizures to stop?’...and wrapping my head around that they aren’t ever going to stop and so how can I make things better for her?” -*Parent 107, parent and child age missing, college degree*. Parent knowledge of clinical outcomes after a decision also influenced their perception of the quality of SDM. These outcomes included downstream benefits or complications from the decision, which retrospectively altered parents’ perception of decision quality. In some cases, knowledge and experience helped parents develop strong preferences and values that guided their child’s care.

Parents’ past caregiving experiences made them more active in present decision-making efforts. Parents often described themselves as an “annoyance” when pushing conversations forward with providers when there were differing opinions or bridging communication among providers. Parents with previous negative decision-making experiences were particularly likely to actively participate in decisions. Many parents described disagreements

with providers. Some parents stopped consulting providers in the face of strong conflicts, preventing the care team from reaching treatment plan consensus. For one family conflict arose because the gastroenterologist prioritized caloric goals over preventing aspiration pneumonia. The parent stopped seeing the gastroenterologist until he agreed to a less aggressive nutrition regimen.

Knowledge factor 3: Parents frequently were concerned over uncertainty in decisions but felt they were under-addressed.

Many parents expressed concerns about their child's uncertain future health trajectory, particularly the lifelong implications of healthcare decisions. We observed two subtypes: (1) uncertainty about the trajectory of an acute illness exacerbation and (2) uncertainty about the child's life-course trajectory. For the former subtype, parents expressed reticence about making decisions when they were unsure how the illness would resolve. For the latter subtype, parents struggled to commit their child to long-term treatments (e.g., feeding tubes, breathing tubes) due to uncertain long-term impacts on their child's development and future technology independence: "when you know there's a risk with everything, how do you decide which way to go?" *-Parent 535, age 24, some college, child age 2 years.*

Some parents appreciated when providers acknowledged these uncertainties and created contingency plans to address uncertainty. For example, one parent wanted her child's gastrostomy tube removed but delayed removal after speaking with her primary pediatrician about timing of removal. "We're going to keep the G-tube in just as a backup. And that kind of alleviates a little bit of my worry because I know that if she's stuffy or whatever, and she can't eat or has a sore throat then she'll be able to still get her feedings." *-Parent 78, age 38, some college, child age 3 months.*

Context factor 1: Health system factors emerged in SDM primarily as unanticipated barriers.

Health system factors overwhelmingly were identified as barriers to SDM and included provider convenience and control. Provider convenience included scheduling issues such as the provider's operating room or rounding schedules that forced a decision to be made. Many parents felt taken off guard when a time horizon for a decision was shortened due to scheduling issues. Provider control sometimes outweighed parental choice because providers served as gatekeepers to executing the decision (e.g., approving durable medical equipment, prescriptions, and outpatient therapies).

Context factor 2: Decision time horizon influenced the degree to which parents participated in decision-making.

The decision time horizon was the time between when the decision was introduced and when the decision was made. Long time horizons spanned years. Decisions with short time horizons were made within the same clinical encounter in which they were introduced and were more likely to be considered urgent. In these instances, parents described deferring to the provider's recommendations or made decisions based on emotions (e.g., fear, frustration). One parent felt pressured to agree to intubate her child for an MRI because her child was already being transported to the MRI machine. "Yeah, I didn't really agree with it

either, but then when you're on the spot you're like, 'Okay.'" -*Parent 214, age 35, college degree, child age 10 years*. Parents ascribed positive feelings to situations when they had a shared understanding with the medical team about the decision time horizon.

The decision time horizon also influenced the degree to which patient factors were considered during decision-making. If a clinical outcome or behavior occurred immediately *prior* to the decision being introduced or in the time *between* introduction of the decision and making the decision, it played a key role in parents justifying selection of a treatment option. For example, test results were often used to justify decisions.

Shared decision-making in the Chronic Care Model

In comparing our results to existing elements in the Chronic Care Model, we identified four unique additions to this model in the context of SDM for CMC, represented in red in Figure 1. The first component was the decision time horizon as an environmental factor that affects the quality of SDM. The remaining three components affected parent-provider interactions during decision-making but were outside of the system-level influences in the Chronic Care Model. These three elements were: parent knowledge and experience, information source, and concern for uncertainty.

Barriers and facilitators

Parents identified recurring opportunities to improve SDM specific to CMC. These opportunities relate to themes around the decision time horizon, integration of patient preferences and values, and uncertainty in decision-making. Poorly defined decision time horizons or differing perceptions of a reasonable decision time horizon hindered both parents' and providers' feeling prepared to reach a decision, with parents frequently feeling rushed into making a decision. Short time horizons, in particular, made parents more hesitant to participate in treatment plan discussions. Also, we found that patient factors were not routinely probed for by clinicians, unless the child recently had an acute clinical issue. Even though CMC tend to have functional impairment that hamper their ability to meaningfully participate in the decision-making conversation, almost all parents described their children as capable of articulating their own preferences. Positive decision-making experiences also occurred when providers acknowledged the uncertainty in the context of the decision. Providers who were able to do so were perceived by parents as a part of the team rather than as an adversary in the decision-making process. Furthermore, providers who could provide contingency plans, accounting for uncertainties, alleviated parental anxiety about making a decision. Long-standing relationships with providers presented both as facilitators and barriers to SDM. Some parents perceived longstanding relationships improved SDM because providers better understood their child's condition. In other cases, longstanding relationships interfered with SDM as medical providers made assumptions about the parent's preferences.

Discussion:

In in-depth interviews with parents of CMC, we identified common and unique elements of SDM, which may help inform interventions designed to improve care for this vulnerable population.

We captured the nine essential elements contained in the prevailing conceptual definition of SDM derived from adults.²³ Most notably, the elements of “making or explicitly deferring a decision” and “decision follow-up” closely relate to our theme around having a shared decision time horizon to successfully engage in SDM. The progression of the decision-making process also fit within the collaborative deliberation model of recognizing alternatives, engaging in comparative learning, and constructing and integrating preferences into the decision.³⁰

We identified three critical opportunities to improve SDM in clinical practice: 1) establish a shared decision time horizon, 2) elicit patient preferences, and 3) acknowledge uncertainty. These opportunities should be applied to decisions with no clear best option, when SDM can be most helpful.¹¹

Parents and providers should establish a shared time horizon for decision-making that accounts for clinical factors (e.g. age, comorbidities, urgency) and system factors (e.g. scheduling constraints, resource availability). This may help parents calibrate their expectations and make them better decision-making partners.

Purposeful elicitation of a child’s preferences and values during decision-making could help keep the child at the center of decision-making, as recommended by the International Patient Decision Aids Standards and National Quality Forum guidelines for developing high quality decision support tools.^{35,36} While many CMC have underlying comorbidities that prevent direct preference elicitation by the provider, all parents of CMC in our study could identify cues for patient preferences. Decision-making should include explicit elicitation of patient’s preferences through their parents.

Additionally, providers should acknowledge uncertainty in decisions and provide contingency plans based on uncertainties. We found that parents frequently felt ill-prepared to make a decision for their child’s health based on the many unknowns about the patient’s future health, and many parents coped with this uncertainty internally. These findings build upon the emerging field of uncertainty communication.³⁷ Three types of uncertainty exist in health care: probability, ambiguity, and complexity. While most research focuses on probability communication, parents in our study struggled with uncertainty from ambiguity and complexity surrounding prognosis and treatment. Uncertainty surrounding risks and benefits of treatment options should be addressed during SDM.³⁸

Our study had several limitations. Recall bias may have affected parents recounting of their decision-making experiences. Overwhelmingly, parents recalled extreme examples of negative or positive interactions. Moreover, decision outcome could color parental perception of decision-making. To alleviate some aspects of recall bias, we asked parents to describe both past and current health decisions for their child. Future research should

include direct observation of decision-making to avoid recall bias. Additionally, our interviews were limited to parents of CMC and therefore do not represent provider or patient perspectives. A balanced representation of parent, patient, and provider perspectives could give a more accurate framework of SDM for CMC overall, and should be the focus of future work. Also, innate biases of coders could influence results. We actively strived to mitigate this effect by including a multidisciplinary team with varied clinical and research backgrounds who coded transcripts independently prior to team meetings.

Conclusion:

SDM has gained prominence as a potential means to improve care quality and health outcomes for CMC. Our findings can guide future interventions and research to improve SDM for CMC. Recognition of a shared time horizon, patient preferences, and the uncertainty inherent in decision-making may improve SDM for CMC.

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Abbreviations:

SDM	shared decision-making
CMC	children with medical complexity

References

1. Committee on Comparative Effectiveness Research. Initial national priorities for comparative effectiveness research. Washington, DC: Institute of Medicine; 2009.
2. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social science & medicine* (1982). 1997;44(5):681–692. [PubMed: 9032835]
3. Fiks AG, Localio AR, Alessandrini EA, Asch DA, Guevara JP. Shared decision-making in pediatrics: a national perspective. *Pediatrics*. 2010;126(2):306–314. [PubMed: 20624804]
4. Wilson SR, Strub P, Buist AS, et al. Shared treatment decision making improves adherence and outcomes in poorly controlled asthma. *American journal of respiratory and critical care medicine*. 2010;181(6):566–577. [PubMed: 20019345]
5. Fiks AG, Mayne SL, Karavite DJ, et al. Parent-reported outcomes of a shared decision-making portal in asthma: a practice-based RCT. *Pediatrics*. 2015;135(4):e965–973. [PubMed: 25755233]
6. Valenzuela JM, Smith LB, Stafford JM, et al. Shared decision-making among caregivers and health care providers of youth with type 1 diabetes. *Journal of clinical psychology in medical settings*. 2014;21(3):234–243. [PubMed: 24952739]
7. Adams RC, Levy SE. Shared Decision-Making and Children With Disabilities: Pathways to Consensus. *Pediatrics*. 2017;139(6).
8. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529–538. [PubMed: 21339266]

9. Lin JL, Cohen E, Sanders LM. Shared Decision Making among Children with Medical Complexity: Results from a Population-Based Survey. *The Journal of pediatrics*. 2018;192(Supplement C):216–222. [PubMed: 29102046]
10. Hummelinck A, Pollock K. Parents' information needs about the treatment of their chronically ill child: a qualitative study. *Patient education and counseling*. 2006;62(2):228–234. [PubMed: 16139981]
11. Wennberg JE. Unwarranted variations in healthcare delivery: implications for academic medical centres. *BMJ (Clinical research ed)*. 2002;325(7370):961–964.
12. Stacey D, Legare F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *The Cochrane database of systematic reviews*. 2017;4:Cd001431. [PubMed: 28402085]
13. Tinetti ME, Naik AD, Dodson JA. Moving From Disease-Centered to Patient Goals-Directed Care for Patients With Multiple Chronic Conditions: Patient Value-Based Care. *JAMA Cardiol*. 2016;1(1):9–10. [PubMed: 27437646]
14. Naik AD, Dindo LN, Van Liew JR, et al. Development of a Clinically Feasible Process for Identifying Individual Health Priorities. *Journal of the American Geriatrics Society*. 2018.
15. Blaum CS, Rosen J, Naik AD, et al. Feasibility of Implementing Patient Priorities Care for Older Adults with Multiple Chronic Conditions. *Journal of the American Geriatrics Society*. 2018.
16. Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? *Effective clinical practice : ECP*. 1998;1(1):2–4. [PubMed: 10345255]
17. Fremion E, Morrison-Jacobus M, Castillo J, Castillo H, Ostermaier K. A chronic care model for spina bifida transition. *Journal of pediatric rehabilitation medicine*. 2017;10(3-4):243–247. [PubMed: 29125512]
18. Adams JS, Wisk LE. Using the Chronic Care Model to Improve Pediatric Chronic Illness Care. *Joint Commission journal on quality and patient safety / Joint Commission Resources*. 2017;43(3):99–100.
19. Adams JS, Woods ER. Redesign of chronic illness care in children and adolescents: evidence for the chronic care model. *Curr Opin Pediatr*. 2016;28(4):428–433. [PubMed: 27138998]
20. Rhee KE, Kessl S, Lindback S, Littman M, El-Kareh RE. Provider views on childhood obesity management in primary care settings: a mixed methods analysis. *BMC health services research*. 2018;18(1):55. [PubMed: 29378579]
21. Kercksmar CM, Beck AF, Sauers-Ford H, et al. Association of an Asthma Improvement Collaborative With Health Care Utilization in Medicaid-Insured Pediatric Patients in an Urban Community. *JAMA pediatrics*. 2017;171(11):1072–1080. [PubMed: 28975221]
22. Stille CJ, Fischer SH, La Pelle N, Dworetzky B, Mazor KM, Cooley WC. Parent partnerships in communication and decision making about subspecialty referrals for children with special needs. *Academic pediatrics*. 2013;13(2):122–132. [PubMed: 23356961]
23. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient education and counseling*. 2006;60(3):301–312. [PubMed: 16051459]
24. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *Journal of general internal medicine*. 2012;27(10):1361–1367. [PubMed: 22618581]
25. Walker D, Myrick F. Grounded theory: an exploration of process and procedure. *Qual Health Res*. 2006;16(4):547–559. [PubMed: 16513996]
26. Garth B, Murphy GC, Reddihough DS. Perceptions of participation: Child patients with a disability in the doctor–parent–child partnership. *Patient education and counseling*. 2009;74(1):45–52. [PubMed: 18760558]
27. Kuo DZ, Goudie A, Cohen E, et al. Inequities in health care needs for children with medical complexity. *Health affairs (Project Hope)*. 2014;33(12):2190–2198. [PubMed: 25489038]
28. Corbin J, Strauss A. Grounded theory research: procedures, canons, and evaluative criteria. *Qualitative Sociology*. 1991;13(1):3–21.
29. Charmaz K. Gathering rich data In: *Constructing grounded theory: a practical guide through qualitative analysis*. SAGE Publications Ltd; 2006:16–18.
30. Elwyn G, Lloyd A, May C, et al. Collaborative deliberation: a model for patient care. *Patient education and counseling*. 2014;97(2):158–164. [PubMed: 25175366]

31. Weiss BD, Mays MZ, Martz W, et al. Quick assessment of literacy in primary care: the newest vital sign. *Annals of family medicine*. 2005;3(6):514–522. [PubMed: 16338915]
32. Strickland BB, Jones JR, Newacheck PW, Bethell CD, Blumberg SJ, Kogan MD. Assessing systems quality in a changing health care environment: the 2009-10 national survey of children with special health care needs. *Maternal and child health journal*. 2015;19(2):353–361. [PubMed: 24912943]
33. Denzin N, Lincoln Y. *Handbook of Qualitative Research*. 2nd ed. Thousand Oaks, CA: Sage; 2000.
34. Dedoose [computer program]. Version 8.0.35. Los Angeles, CA: SocioCultural Research Consultants, LLC; 2018.
35. Elwyn G, O'Connor A, Stacey D, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ (Clinical research ed)*. 2006;333(7565):417.
36. National Quality Forum. National standards for the certification of patient decision aids. 12 15, 2016.
37. Han PKJ, Klein WMP, Arora NK. Varieties of uncertainty in health care: A conceptual taxonomy. *Medical Decision Making*. 2011;31(6):828–838. [PubMed: 22067431]
38. Parascandola M, Hawkins J, Danis M. Patient autonomy and the challenge of clinical uncertainty. *Kennedy Institute of Ethics journal*. 2002;12(3):245–264. [PubMed: 12472078]

Adapted from the Chronic Care Model¹⁶

Figure 1.
Shared decision-making for children with medical complexity within the Chronic Care Model

Table 1.

Characteristics of parent participants

Characteristic	Total (%) n=32
Age- mean (SD)	33.9 (7.4)
Sex- female	27 (84.3)
Interview Language- English	27 (84.3)
Race/Ethnicity	
Caucasian	7 (21.9)
African American	1 (3.1)
Alaskan Native	1 (3.1)
Asian	4 (12.5)
Pacific Islander	1 (3.1)
Hispanic	18 (56.3)
Insurance	
Medicaid	6 (18.8)
Private	10 (31.3)
Indian Health Service	1 (3.1)
State Children's Health Insurance Program	6 (18.8)
Medicare	2 (6.3)
Other	5 (15.6)
Don't know	1 (3.1)
Household size- mean (SD)	4.9 (1.6)
Marital Status	
Single	5 (15.6)
Married	22 (68.8)
Living with partner	4 (12.5)
Single, divorced	1 (3.1)
Household Income	
\$0-24,999	10 (31.3)
\$25,000-49,999	6 (18.8)
\$50,000-74,999	6 (18.8)
\$75,000-99,999	0 (0)
\$100,000-124,999	3 (9.4)
\$125,000-149,999	2 (6.3)
\$150,000+	2 (6.3)
Education Level	
Some high school	3 (9.4)
High school diploma	3 (9.4)
Some college	15 (46.9)
College degree	9 (28.1)
Advanced degree	2 (6.3)
SDM Questions Composite- with high SDM	26 (81.3)

Characteristic	Total (%) n=32
Newest Vital Sign Low Health Literacy (less than 4 correct responses)	15 (46.9)

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Table 2 online.

Characteristics of children of parent participants

Child Characteristics	Total (%) n=32
Age- mean (SD)	4.2 (4.1)
Sex- Female	14 (43.8)
Race/Ethnicity	
Caucasian	8 (25)
African American	0 (0)
Alaskan Native	1 (3.1)
Asian	4 (12.5)
Pacific Islander	1 (3.1)
Hispanic	20 (62.5)
Children with Special Health Care Needs Screener questions	
Needs or uses prescription medicines	24 (75)
Needs or uses more medical care than usual	23 (71.9)
Functional limitations more than usual	32 (100)
Needs or uses special therapies	21 (65.6)
Needs or uses treatment for emotional/developmental/behavioral issues	13 (40.6)
Subspecialists	
Cardiology	10 (31.3)
Neurology	13 (40.6)
Pulmonology	13 (40.6)
Development	7 (21.9)
Gastroenterology	17 (53.1)
Occupational therapy	16 (50)
Speech therapy	12 (37.5)
Physical therapy	15 (46.9)
Other	5 (15.6)
Technology dependence	
Ventriculoperitoneal shunt	3 (9.4)
Gastrostomy tube	13 (41.6)
Tracheostomy	5 (15.6)
Other	3 (9.4)
None	8 (25)
Neurodevelopmental delay	
Intellectual disability	2 (6.3)
Cerebral palsy	6 (18.8)
Visual impairment	10 (31.3)
Hearing deficit	2 (6.3)
None	17 (53.1)

Table 3 online.

Thematic findings with sample quotes

Subtheme	Quote
Participant themes	
Participant Theme 1: Patient clinical outcomes are used in decision-making while patient preferences are readily attainable but underutilized.	
<i>Clinical outcomes affect decisions</i>	"But if it's something that after this bronch, he's still going to have a little bit more time [with the tracheostomy], then it's a conversation that I would want to address to see if we can get that [speaking] valve]" -Parent 965, age 36, college degree, child age 11 months
<i>Preferences are attainable</i>	"I've talked to [the patient] a lot lately about how she feels about all this stuff with increased seizures and the hurt [it causes]." -Parent 443, age 33, some college, child age 10 years
Participant Theme 2: Parents overall felt they should be in control of decision-making	
	"it's my child, so I don't care whose feelings I hurt or what someone or whatever thinks of me...I want to make sure I'm making good decisions and staying on top of things so he can get healthier" Parent 715, age 31, some college, child age 3 years
<i>Emotion and beliefs</i>	"We were supposed [take him off levothyroxine] last summer but I chickened out and I didn't want to take him off because I was kind of scared." -Parent 364, age 36, some college, child age 5 years
<i>Parental convenience</i>	"it was really hard for us to go out and having her on continuous feeding during the night" -Parent 305, age 24, high school diploma, child age 5 years
<i>Parent-centered</i>	"I don't want to say I'm fed up. But I'm just tired of trying to find the solution for a lot of things when it would be a lot easier if he could possibly bend [after surgery], then it wouldn't be so hard on me." -Parent 536, age 32, some college, child age 9 years
Participant Theme 3: Providers determine the urgency of the decision and reallocate decision ownership.	
	"the heart surgeon arrived and he told me that he was going to operate as soon as the operating room was available...It's because he could no longer breathe, and he was in a critical condition."- Parent 790, age 42, child age 22 months, some college
Knowledge themes	
Knowledge factor 1: The source of information affects the influence that information has on the decision.	
<i>Non-professional sources of information valued</i>	"[Amazon] It's real life reviews, not just ones that...somebody's getting paid. From real people. Yeah. Real people, real stories." -Parent 187, age 36, college degree, child age 10 years
<i>Conflicting provider perspectives viewed as information</i>	"they were debating on whether-- what to do, what not to do [about the lung mass]...The only way to keep us involved is by just giving us information...we want to be like, 'Hey, this is what's going on. This is what the doctors think. What do you guys think? So we could talk about it over with the doctors and see what should we do going forward'" -Parent 629, age 21, some college, child age 3 months
Knowledge factor 2: Greater parent knowledge and experience helped parents play a more active role in decisions.	
<i>Preference formation</i>	"I wanted to stop her getting pneumonia because every time [we increased her feeds] she was getting pneumonia, we wound up in the ER and then we stay a month in the hospital." -Parent 305, age 24, high school diploma, child age 5 years
<i>Parent agency</i>	"You learn from an experience that you go through and you're prepared next time to say, 'Okay. These are the steps. This is what's going to happen. It's going to get better. These are my options. This is what I can do.'" - Parent 725, age 36, college degree, child age 18 months
<i>Information as power</i>	"When you talking that is when you have the information, and you know can get the get the service. You don't talk to just because you can. You'll be talking, because you know it will help..." -Parent 447, age 41, some high school, child age 3 years
Knowledge factor 3: Parents frequently were concerned over uncertainty in decisions but felt they were under-addressed.	
<i>Uncertainty of life trajectory</i>	"One thing I've always learned from the unknowns from her if we can't figure out what the problems is now, what do we do if it happens again? Let's put a plan in place now. Not tomorrow. Now." -Parent 498, parent and child age missing, some college
<i>Uncertainty of illness trajectory</i>	"every time we go in the hospital they're like, 'You have one almost three year old and he's not trached'... nine months ago Pulmonology told me within six months or less, he's probably going to be trached and I'm like, 'No.' It's been over nine months now since he told me that, so I'm like, 'Yes.'" -Parent 864, age 31, some college, child age 3 years
Context themes	

Subtheme	Quote
<i>Context factor 1: Health system factors emerged in SDM primarily as unanticipated barriers.</i>	
	“the neurologist wasn’t on-call, so he wasn’t at the hospital. So his colleague was there seeing us, seeing him. He introduced an entirely new seizure medication. Like he made that call and introduced the new medication. And that wasn’t in the action plan.” -Parent 784, age missing, some college, child age 10 years
<i>Context factor 2: Decision time horizon influenced the degree to which parents participated in decision-making.</i>	
	“We had a pericardiocentesis...what made us make that decision was I think knowing that it was completely out of our control. Meaning that she could die in ten minutes, or she could die in ten days, or she could die in ten months if we didn’t address this issue.” -Parent 449, age 31, college degree, child 11 years