The Healing Health Care Team

White Paper

David A. Bergman, Sandra Hassink, Sarah Ronis, Kurt C. Stange, Christina D. Bethell

The development of this white paper was supported by a grant to Johns Hopkins Bloomberg School of Public Health from the Robert Wood Johnson Foundation (#75448).

The Child and Adolescent Health Measurement Initiative
December 2022
Author’s information:

David A. Bergman: Department of Pediatrics Stanford University School of Medicine, 1210 Pitman Ave. Palo Alto, CA 94301 daberg@stanford.edu

Sandra Hassink: Emeritus, Nemours Children's Health System, 2602 Pennington Dr. Wilmington, DE 19810 Sandra.hassink@nemours.org

Sarah Ronis: Department of Pediatrics Case Western Reserve University, 11100 Euclid Ave Cleveland, OH 44106 Sarah.Ronis@UHhospitals.org

Kurt C. Stange: Center for Community Health Integration, Case Western Reserve University, Suite 406 BioEnterprise Building, 11000 Cedar Ave., Suite 402, Cleveland, OH 44106 kcs@case.edu

Christina D. Bethell: Department of Population, Family and Reproductive Health, Child and Adolescent Health Measurement Initiative, Johns Hopkins Bloomberg School of Public Health, 615 N Wolfe Street, Room E4152 Baltimore, MD 21205 cbethell@JHU.edu

Citation:

Citation: David A. Bergman, Sandra Hassink, Sarah Ronis, Kurt C. Stange, Christina D. Bethell. 2022. The Healing Health Care Team White paper. The Child and Adolescent Health Measurement Initiative. Available at: https://www.cahmi.org/resources. Accessed: [dd/mm/yyyy].

Abbreviations:

HHT: Healing Health Care Team
PTSD: Post Traumatic Stress Disorder
COVID 19: Coronavirus Disease 2019
EHR: Electronic Health Record
SPOC: Shared Plan of Care
ED: Emergency Department
COE: Cycle of Engagement
Summary

As team-based health care assumes growing prominence, it is important to translate research on the central importance of the healing relationship in the patient/family and doctor dyad to relationships in the context of health care teams. We propose a healing health care team (HHT) which draws on key components of the healing relationship and melds them with more typically known attributes of the highly effective team. Attributes of the HHT include valuing the patient/family and all team members, being present during patient/family encounters and during team exchanges, sharing power and decision making with the patient/family and across team members and providing adaptability, consistency and continuity in patient/family care and in team operations.

The HHT provides an opportunity for transformative change to heal ailing patients, burned out health care providers, and an ailing health care system. Putting the HHT into practice in most settings requires cultural changes, new tools and workflows for enhanced communication, sufficient time with the family and the development of the shared plan of care. It also requires skills and knowledge of the science elucidating the essential role of attuned, trusting relationships in order to engage both patients in their own healing and teams in the shared purpose and focus required to provide efficient and effective care. Innovations and further research on HHT in pediatric practice is recommended to assess impact on children, families and providers of care, cost, utilization, services quality and quality of life.
Introduction

Traditionally the treatment of the child has been anchored in both the art and science of medicine. The science of medicine has been flourishing, for example, both precision medicine and genomics have led to a rapid increase in our understanding of disease\(^1\) leading to new and revolutionary treatments that target the molecular origins of disease and are tailored to the unique genetic makeup of the patient.\(^2\) However, despite these important technical advances, the prevalence of disease, rates of death and gaps and inequalities in health and well-being for children and adults are greater than ever.\(^3,4\) At the same time the socially-, behaviorally-, and environmentally-mediated reductions in health are burgeoning. Addressing and impacting the health effects of these factors requires attention to contextual and relational elements in children’s and family’s lives and perhaps improvement in these discouraging health metrics can be found less in the science of medicine and more in the power of healing relationships.

The central premise of this paper is that art of medicine is embodied in the human connection and caring relationships that are central to health and well-being.\(^5\) It is through these connections that we provide healing in the lives of adults, children, families and communities.\(^6-9\) Traditionally, health care relationships have been the purview of the physician and other clinicians\(^5, 10\) and healing relationships have been defined in this context of dyadic relationship between the provider and family. However, the increasing complexity of health care, and the evolving organization of health care all have validated increasing team approaches to care.\(^11-16\) This evolution to team-based care raises the important question of how caring relationships can be articulated between members of a health care team and with the family, largely uncharted territory in the medical literature.\(^17\) This paper will outline the key premises supporting investments in creating healing health care teams and the key attributes and requirements to articulate the cultural changes, tools, and workflows necessary for a healing health care team (HHT). It is one in a set of papers advanced through the “We Are the Medicine: Relationships Are the Heart of Healing” working group led by the Child and Adolescent Health Measurement Initiative to advance the Prioritizing Possibilities for Child and Family Well Being national agenda and with support from the Robert Wood Johnson Foundation.
The Power of Caring Connections

The scientific evidence supporting the power of caring relationships to promote the healing aspect of medicine is considerable and speaks to the needs of clinicians, patients and families.\textsuperscript{5} Research has largely involved adults and demonstrated the fundamental role of healthy relationships for early and lifelong health, including the impact of a lack of human connection among adults on population level increases in morbidity and mortality.\textsuperscript{18} Loneliness and social isolation have been shown to be significant risk factors for death from all causes even in the absence of disease.\textsuperscript{19} This is particularly true for vulnerable populations such as the elderly where feeling lonely was associated with a 50% increased risk of declining functional status and death\textsuperscript{20}. Research has also shown that positive social connections with health care providers have a direct healing effect on patients. Provider demonstrations of compassion has been shown to lower blood pressure,\textsuperscript{21-24} promote healing from trauma\textsuperscript{25}, positively modulate pain\textsuperscript{26, 27} and improve palliative care outcomes\textsuperscript{18}. Health care provider acts of compassion and caring have also been shown to significantly improve the medical outcomes in diabetes\textsuperscript{28}, heart disease\textsuperscript{29} and wound healing\textsuperscript{30, 31}. Similar positive outcomes are found for behavioral health conditions such as depression\textsuperscript{32}, anxiety\textsuperscript{33, 34} and PTSD (post-traumatic stress disorder)\textsuperscript{24}. Compassionate and caring care has also been associated with activation of self-care in patients\textsuperscript{35}, improved health care quality and safety outcomes\textsuperscript{36-39}, and even utilization and cost reduction\textsuperscript{39, 40}. Compassion and caring have a positive impact on the dynamic of the patient-clinician relationship\textsuperscript{41, 42} — and therein lies further opportunity to advance child and family health.

Caring connections are particularly germane for children all of whom require safe, stable, nurturing relationships which provide the building blocks of healthy development and flourishing across life\textsuperscript{43}. Yet, a recent national study documents that fewer than half of families demonstrate the resilience and parent-child connection essential to child development and flourishing; and only 40% of all school age children meet criteria for developing into flourishing adults, such as being curious and interested in learning, persisting to complete tasks and being able to recognize and regulation emotions and behaviors\textsuperscript{43}. These are characteristics that are developed through strong families that prioritize connection and healthy relationships. It is a
central role to promote such family strengths in pediatrics, which in turn requires strong family-provider relationships.

Caring Connections: A recipe for post COVID-19 era

Caring relationships are not only important for the patient and family. Their absence can have a profound impact on the clinician. Currently up to 40% of physicians experience practice burnout, and significant numbers experience depression, exhaustion and find no meaning in their work. These adverse impacts on clinicians have led to increased errors, poor physician-patient communication and lower ratings of patient experience. Under the new stress introduced by the COVID-19 pandemic, the need for caring, compassionate and trusting connection is even greater and yet also potentially harder. This pandemic has been layered onto an environment where many clinicians feel that they practice in a dysfunctional work world fraught with rapid technological interventions such as electronic health records (EHR) which often create hours of what is perceived as busy work lacking value for patient outcomes. High rates of burnout extend to the health care team. Care teams face ongoing and new stresses that make it more difficult to develop or sustain caring, compassion and trusting relationships in the face of the of an unforgiving disease that is often demanding and exhausting to treat and often leaves the clinician as the sole source of solace for a dying or worried patient. Research on the patient-centered medical home shows that successful practice development involves not only relationships with patients, but with changes that strengthen practices' core sense of connection and teamwork, build adaptive reserve, and expand attentiveness to the local environment.

Even prior to the pandemic this problem of practice burnout and moral injury was widespread. Today clinicians will often spend 2 hours of time documenting care for every hour spent with the patient leaving less time for the critical interactions that foster healing relationships. Clinicians are also feeling loss of autonomy and control over the delivery of care. What had been previously physician owned practices are now transitioning to practices that are part of large health care systems. The incentives in these large systems encourage clinicians to order more tests, spend less time to see patients, and refer to more specialists in order to maximize revenue in a fee for service system. This emphasis on the “production” forces
clinicians to practice medicine in a way that is not meaningful to them and does not prioritize the well-being of their patients\textsuperscript{57}.

Clinicians in the pandemic are looking for an antidote to the trauma of caring for COVID-19 patients.\textsuperscript{58} This antidote resides in the development trusting and nourishing relationships between the patient/family and the clinician — relationships which result in hope, trust and a sense that your clinician knows who you are.\textsuperscript{59} These trusting relationships, which are essentially healing relationships, however are not automatically conferred by the family; they must be earned and they are earned by providing presence, compassion and caring\textsuperscript{60} \textsuperscript{60-62}.

**Healing and the Healing Relationship**

Healing has multiple definitions that have at their core a “holistic, transformative process of repair and recovery in mind, body, and spirit resulting in positive change”\textsuperscript{63}. The healing relationship is then the relational container in which healing can be facilitated. It is a dynamic process of recovering from a trauma or illness by working toward realistic goals, restoring function, and regaining a personal sense of balance and peace. Factors that facilitate the healing relationship include building relationships, improving communication, and sharing responsibility between the patient and clinician.\textsuperscript{17} Traditionally curing has been the primary goal of western medicine. However, in recent years there has been movement to a more holistic approach that incorporates healing and the relief of suffering in the approach to the patient. Suffering patients say that they would like to be cured, but when that is not possible, as in the case of the growing prevalence of (often multiple) chronic illnesses, patient would like to be healed, with healing understood as transcending or finding meaning in suffering.\textsuperscript{7} This has led to research in the medical and nursing literature on what constitutes a healing relationship.\textsuperscript{17, 64-67} For the purpose of discussion we have chosen a model for the healing relationship proposed by JG Scott et al\textsuperscript{61}. This model has been empirically derived from extensive qualitative analysis with physicians and patients as a template to describe the characteristics of a healing relationship. The key processes that foster healing relationships are presented below.

- **Valuing/creating a non-judgmental bond:** Being able to value the patient and family and establish an emotional bond within the context of the encounter in a manner that is
non-judgmental where the patient/family feels they are valued regardless, of their role, social situation, ethnicity, life circumstances or type of insurance.

- **Presence**: Being present in the encounter through giving full attention to the patient/family, listening to their stories and being able to both experience and empathize with their suffering and joy. It is important the patient/family does not feel rushed and that their story can be heard without distractions.

- **Sharing Power**: Acknowledging the power differential between patient/family and clinician — often partnering with the patient/family in making shared decisions, respecting the parent as the expert about themselves and their child in decision making and accountability, and translating medical jargon into a language and literacy level that patients/families understand, and which enables them to learn; sometimes using the power differential to push the patient toward a transformative experience.

- **Abiding**: Being there for families to provide a continuity of caring experiences through a commitment for caring for patients over time, being present during times of health care crises and providing a belief that you will not give up even if you are not able to provide a cure.

Three relational outcomes result from these processes: trust, hope, and a sense of being known. Clinician competencies that facilitate these processes are self-confidence, emotional self-management, mindfulness, and knowledge. How then do these learnings translate into more complex environments where patients and families are cared for by multiple clinicians and health care providers?

**Healing Encounters Benefit from Effective Health Care Teams**

Compassion and caring relationships have traditionally occurred in the context of a trusting relationship between the clinician and the patient. However, for children who have complex chronic conditions, care is provided by a team of clinicians often acting in isolation. Patients with chronic conditions have on average 5 or more physicians involved in their care. In one clinic caring for children with medical complexity, each child had 6 or more pediatric specialists involved in their care. In addition, families interacted with more than 30 community agencies such as schools, and rehabilitative services. Having multiple providers frequently
results in poor communication, varying values around patient care, and uneven access to team members. This can lead to fragmentation of care with a lack of coordination in test ordering, clinical decision making and the development of patient centered goals.\textsuperscript{79, 80} This has placed a considerable burden on families with families spending 11-20 hours per week in care coordination.\textsuperscript{81} More importantly, patients and families often do not feel they are equal partners on the team in spite of being able to bring a unique body of knowledge to the care process.\textsuperscript{82} Frequently families don’t know the members of their health care team. More concerning, members of the health care team do not know that they are members of the team.

Effective team based care has been shown to expand access to care, provide more effective and efficient delivery of services that are essential to care such as patient education, behavioral health, self-management support and care coordination.\textsuperscript{83} In addition, effective team training programs lead to improved team member communication skills, improved team behavior and work performance, and a positive change in the practice safety climate.\textsuperscript{84} There has been considerable research documenting the components of a highly effective team such as:

- **Strong leadership:** the coordination of team members’ activities, and the articulation of clear roles and accountability for team members

- **Flexibility and adaptability:** Flexing team leadership and team membership to meet the needs of a particular tasks. For some situations the pediatric specialist may be the best leader, or an allied health professional may need to join the team

- **Shared values:** Developing shared values that align with the family’s values and priorities

- **Effective communication:** prioritizing consistent and continuous lines of communication and facilitation of shared decision making between team members.\textsuperscript{85-87}

Team maturation has been described as a developmental process,\textsuperscript{88-94} that requires attention similar to the nurturing required for relationships with patients and families.\textsuperscript{95} Unfortunately, the idea of a highly effective team has not been widely realized in health care and is not a skill that is taught to health care professionals.\textsuperscript{96} There remains a persistent gap between what we know comprises a healing relationship and what occurs in the current environment of team-based care.\textsuperscript{97} The closing of this gap calls for a reconceptualization of the healing relationship in the context of the health care team into what we are calling the Healing Health Care Team (HHT).
Putting the Healing Health Care Team into practice

Table 1 delineates attributes that characterize HHTs across each of the key processes of the healing relationship summarized above. The successful implementation of the HHT will require operationalization of these attributes through the employment of new tools and workflows some of which we discuss below.

Valuing the child and family

The cornerstone of valuing the patient and family is the fostering of shared knowledge and values with the patient and family and between team members. Team members need to appreciate each other without regard to their training or role. Valuing can also be reflected in the definition of clear roles for each team member and that these roles may change depending on the clinical issue that needs to be resolved. The iterative process of developing shared plan of care (SPOC) can be leveraged to achieve this goal by basing this process on the foundation of information about family strengths, goals, worries, whole-life context and priorities. Through a comprehensive assessment of these factors the HHT can work to develop shared patient centered goals that align values of the team with those of the family. These goals can range from short term goals such as removal of a gastric tube so the child can eat on their own to more aspirational goals related to a child’s future educational attainment and work in the world. The codification of needs, strengths, and goals into a SPOC that helps to ensure there is a dynamic document in the EHR that can be shared with the family and the health care team. Shared team values also play an important role in valuing the child and family. Team members need to be non-judgmental and empathetic to family concerns, honest and transparent in their communications with the family and with other team members and have humility in recognizing that one type of training or perspective is superior.

Being present for the child and family and providing continuity of care

Just as team members must be available to each other to develop their team function, being present for the child and family calls for the family both to know how to access the team when needed and for the clinician to provide a clinical encounter that fosters a trusting and caring relationship. Easy access to team members is of paramount importance for families. Usually this is best accomplished through a continuous relationship with a team member. Some
families, however, prefer not to have another team member act as a “middleman” in their communications with the HHT or find they can effectively relate to multiple members of the team. Knowing who and when to call and for what reasons can be problematic for many families. One solution is to use access plans which identify common situations where the patient is likely to need care in the ED and/or be hospitalized. For each of these conditions, the access plan articulates how to prevent the clinical condition from arising, who to call and what to do when it occurs, what to monitor to see if the child is improving or worsening and when to go directly to the ED or call 911. These type of access plans have been shown to reduce both ED utilization and hospitalization in children. The use of community health care workers or parent navigators who come from the surrounding community can increase family experience of an abiding presence by helping them overcome language and cultural barriers that can impede the acquisition of shared medical knowledge and navigation through complex health care systems.

Being present for the family requires explicit intention, sufficient skills and patience and time. Because this is often difficult to accomplish in the context of a 20-minute encounter, clinics that specialize in caring for patients with medical complexity often lengthen the encounter to one or more hours. Also, while more time is satisfying for both the family and provider, it often does not meet the short-term goal of maximizing revenue leaving the clinician in a moral quandary of how to address the needs of the patient and family while meeting revenue targets. One interesting idea that has been proposed is payment for optimizing time spent to develop healing relationships. Alternative payment models have been proposed that reward time spend with the family to in order to increase value. The visit time can also be extended through more effective use of pre-visit and post-visit care.

More time does not necessarily result in a healing relationship. The time must be used wisely. Bethell, et al have developed the Cycle of Engagement (COE) model and tools to use patient care time more effectively through the development of relationship-centered approaches to care that focus encounters on the child/family agenda and processes to develop SPOCs based on the child/family content and their priorities and needs. See Figure 1 The COE optimizes time during encounters to build healing relationships by leveraging pre and post visit time to continuously engage families. For example, the COE Well Visit Planner® tool allows caregivers to identify strengths, goals, and concerns, complete nationally recommended assessments
aligned with the Bright Futures guidelines, select their priorities and receive a personalized guide that is shared with the care team to customize and focus care on the family agenda.\textsuperscript{105,106} After visits, caregivers can complete the Promoting Healthy Development Survey to assess what was accomplished during the visit, what was missed and what can be improved, engaging them as partners in improving quality. This allows for an extension of the encounter beyond the face-to-face visit and supports the parent in promoting the health and well-being of their child. It also fosters trusting relationships between families and providers, and in doing so, facilitates the effective provision of critical anticipatory guidance, education and shared decision making to address risks and co-identify follow up steps. This approach has been tested in numerous clinical practices and shown to improve caregiver experience of care, rates of screening and follow up as well decreasing unnecessary use of urgent care.\textsuperscript{106} The use of digital health is another way to extend the encounter by creating more touches with the child and family without the burden of the parent missing work or having to transport a child with medical equipment.\textsuperscript{107, 108} These visits also help overcome the family’s fear of contracting COVID-19 increasing the likelihood of attending the visit.

\textbf{Sharing power}

Just as effective teams partner with each other, partnering with families mandates that the family member be an equal member of the team whose values and preferences are elicited and considered in all decisions.\textsuperscript{109} This often requires a culture change that involves sharing power and flattening organizational hierarchies. The result of this investment in culture change can be an unleashing of energy from both team members and families. This sharing of power is fostered through a culture that recognizes the primacy of the family and brings their unique expertise to decisions about their child. Members of the health care team need to recognize the family as the fundamental unit of health care delivery and accountable with the other team members for the achievement of shared goals. Partnering with families requires that the family be able to integrate new knowledge. This again underscores the importance of health literacy when communicating with families, and of recognizing the complementary strengths of team members who may share cultural congruence or different communication opportunities with diverse families.

\textbf{Consistency and abiding: providing continuity}
Providing continuity and consistency in the family’s care experience is essential for the
development of healing relationships. This is particularly true during times of health care crises.
Practically speaking the HHT should provide the family with clear guidance and instructions on
how to connect with a designated team member, 24x7 and ensure that knowledge of these health
events is shared within the HHT. The development of these abiding relationships between a
family and an HHT requires a high degree of communication among team members and
consonance in values and goals between team members and the family. Much of the needed
communication to identify family goals can take place in the course of normal care processes,
like during the provision of preventive care or the development of the SPOC. Here there is a
recognition that both families and each team member need to weigh in and be comfortable with
the feasibility and value of jointly defined goals, actions and interventions needed to achieve
them. Having a high level of agreement helps to ensure continuity between different team
members. This is particularly important in understanding the equipoise between curative and
palliative care in children with severe chronic conditions by demonstrating to families that their
doctors and care team are still engaged and will not give up even though a cure is not
forthcoming.

Traditionally, communication between the family team member and others on the team,
occurs through a single provider. However, it is important to create systems that support
development of ongoing patient/family relationships with multiple members of the team. There
are a number of workflows that can help achieve this goal. These include alerts to the health care
team about changes in health status such as hospital admissions and ED visits, and frequent
communications between health team members either through the EHR or during huddles before
the visit. The use of mutually agreed upon evidence based diagnostic procedures and treatment
plans can be used to ensure good communication and between team member and with families
and to provide consistency among team members in the care they provide. Sharing family
agendas across care team members, like those produced using tools like the Well Visit Planner,®
can be powerful to foster effective coordination of care around the specific goals, needs and
priorities for each child and family. Creating clinical environments where clinicians are working
closely together in multi-disciplinary programs such as spina bifida or aerodigestive clinics help
to facilitate communication among clinicians, other members of the care team and the family.
Call to Action

The full implementation of the HHT calls for important changes in the culture and practice of pediatrics. This includes:

- A full realization that team-based care is the norm for pediatric practice and there needs to be energy and resources dedicated to building the HHT.
- A reinterpretation of the traditional hierarchies in medicine so that each member of the team is perceived as valued.
- Each member of the HHT being present for each other, sharing power, and valuing each team member.
- A culture change in pediatric practice such that the family is recognized as an equal member of the health care team.
- A clear focus on relationship building as an essential component of the patient/family encounter with team members.

Conclusion

The last decade has been witness to transformational changes in health care. Research on how healing relationships affect outcomes of care has also grown substantially. However, the translation of the healing relationship from the dyadic clinician patient relationship to health care teams has remained under-researched and under-supported. We have characterized key attributes of healing relationships — valuing, being present, sharing power and providing continuity over time — and integrated these with established qualities of highly effective teams — strong leadership, shared values, effective communication, adaptability to new experiences and shared decision making — to define the Healing Health Care Team (HHT). The development of HHTs is particularly relevant during the COVID-19 pandemic and in the team-focused health care system likely to emerge in the post-pandemic era.

The development and implementation of the HHT is a complex yet rewarding task calling for the development of shared values between team members, enhanced communication among team members and the development of patient and family led agendas in the provision of care and development of shared plans of care. Essential to the transformation of children’s health services, the HHT requires realignment of incentives to reward the optimization of patient and
family experience, quality of life and health care outcomes associated with healing relationships.\textsuperscript{50, 89} The similarity between the human connections needed to support healing relationships and team function, and the meaningfulness of those relationships for both patients and health care providers, bodes well for motivating the needed investment in supportive systems and human attention.

This paper has presented a conceptual model of the HHT. Further refinement and understanding of this model will require additional qualitative and quantitative research to better understand how different patients relate to the HHT. There is a compelling need for further research on the impact of the HHT on health outcomes. This needs to include both relational outcomes such as whether the child and family feel they are known and understood, and the degree of trust between the family and the provider, as well as more conventional outcomes such as patient experience, health care utilization and disease related outcomes such hemoglobin A1C. Additional research is also needed to assess the impact of value-based payment plans of the healing team on utilization, health care costs, patient experience, patient quality of life and clinical outcomes. Hopefully this research will lead to a future where the borders between the art and science of medicine are blurred\textsuperscript{110} and we have an intimate understanding of caring and the ability to exquisitely tailor our caring encounters to needs of our patients and families.
References


35. Barker I, Steventon A, Deeny S. Patient activation is associated with fewer visits to both general practice and emergency departments: a cross-sectional study of patients with long-term conditions. *Clin Med (Lond)*. Jun 2017;17(Suppl 3):s15. doi:10.7861/clinmedicine.17-3-s15


102. Crezee IM, Roat C. Bilingual patient navigator or healthcare interpreter: What’s the difference and why does it matter? Cogent Medicine. 2018;6(1)
https://www.cochranelibrary.com/collections doi/SC000043/full
Figure 1. Illustration of the Cycle of Engagement model for early childhood well child services using the Well Visit Planner®\textsuperscript{105,106} (see www.cycleofengagement.org)
### Table 1 Attributes of the Healing Healthcare Team

<table>
<thead>
<tr>
<th>Healing Relationships</th>
<th>The Healing Health Care Team</th>
</tr>
</thead>
</table>
| Valuing the patient and the family and all team members | • Shares information about patient values, and subjective experiences among team members  
• Shares values as team members e.g. being non-judgmental, empathizing with patient’s challenges and illness experience  
• Align team values with those of the patient/family  
• Acknowledge that the family is at the center of the team and an important partner in all decisions |
| Being present for the child and family and in team exchanges | • 24x7 access to a team member  
• Ensure a single point of contact or lead to be primary relationship for patient (may change with changing clinical situation, but patients know this)  
• Schedule enough time for the lead clinician to connect with patient’s experience of illness  
• Create an access plan with patients that ensure contact with a team member during major health care crises (use of texting and mobile phones) |
| Sharing power: partnering with families | • Partner with patient/family as equal member of the team  
• Create the conditions for effective shared decision making with patients about priorities, needs, diagnosis and treatment between team members  
• Will ensure joint accountability in the team towards achievement of patient centered goals  
• Investing in relationship through many little actions, and using the resulting trust to be trustworthy in supporting and/or pushing the patient/family when helpful |
| Consistency and abiding; providing Continuity | • Use team members to expand availability and connection  
• Engage in frequent team communication, for example, by using huddles  
• Use evidence-based protocols to increase consistency in clinical practice among team members, while also providing individualization and tailoring to patient/family particulars  
• Form multidisciplinary clinics (physical or virtual) that allow shared communication between pediatric specialists and the family |