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Social determinants of comfort: A new way of conceptualizing pediatric end-of-life care

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Introduction

2-year-old Kayla was admitted to the Pediatric ICU for pneumonia. At her baseline, she has spastic quadriplegia and epilepsy from cerebral palsy. During this hospitalization, she required mechanical ventilation and now has a tracheostomy. This will impact the care she needs at home, as well as the trajectory of her disease progression. Her parents were having difficulty taking care of her before, especially because of the impact of Kayla's care on their other children. The rural area where they live has a strong community, but there are few resources there to assist with Kayla's needs.

6-week-old Tyler is in the NICU, having been born with Edwards' Syndrome (Trisomy 18). He has required a great deal of ICU support, and his life is expected to be short. A palliative care nurse practitioner stopped in and asked his nurse when he expected a parent to be at the bedside. "Good luck! They're never here," he said, rolling his eyes. The nurse practitioner reached Tyler's mother, Emma, by phone. "Thanks, but no thanks," Emma responded. "You people judge me for not being there, but what should I do? I have to take the bus there and I have other kids at home. I don't need to move heaven and earth to come in and listen to someone tell me to give up on my son."

11-year-old Madison has been undergoing treatment for leukemia for 5 years. She initially achieved remission, but this was short-lived. It is becoming clear that the cancer has the upper hand and that Madison's chances of survival are increasingly poor. She is stoic and

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uncomplaining, but it is obvious that she is suffering. Some of her nurses believe she would benefit from a concurrent approach that would allow her to continue to receive life-prolonging interventions while also receiving measures to make her more comfortable. However, her physicians have brushed these suggestions to the side. “We need to have hope,” her oncologist said. “And the family needs us to give them hope.”

In the busy and stressful landscape of units, wards, and clinics that care for children with life-limiting illnesses and their families, the context within which a child and family live, work, play, and grow can be forgotten. The immediacy of sustaining life and making medical decisions can lead the most well-intended clinician to forget what lies beyond the four walls of the patient room or clinic for that child and their family. As the vignettes above illustrate, not understanding the complexity of a child’s context can adversely impact the care provided. These children and their families encounter barriers to resources needed for daily life demands and management of chronic health needs. They often must navigate such barriers and risk factors while working with the health care systems and their respective bureaucracies. This navigating can cause families to experience additional trauma and ongoing health inequity.

In prior work, the concept of social determinants of comfort (SDOC) described structural conditions that influence whether, to what degree, and in what forms comfort measures are offered to and accepted by patients and their families.[1] SDOC include socioeconomic status, education, geographic area, physical environment, employment, social supports, and access to care. The definition is based on the etymology of the term comfort, which comes from Latin *confortare,* meaning to “strengthen greatly.”[2] Social determinants of comfort (strength) at the end of life highlight the importance of making families stronger by reducing family burden and stress and improving access to supportive services.

This notion of social determinants of comfort builds on the well-accepted concept of social determinants of health. Guiding palliative care documents begin to address this intersection. The National Consensus Project describes the eight domains of quality palliative care: addressing the social determinants of health falls within the domains of social care, cultural care, and ethical care.[3] In this document, the authors acknowledge that the impact of serious illness extends beyond the bodily health of the patient. Serious illness affects – and is affected by – every facet of the lives of patients and families. Thus, variations in the comfort measures that are available, offered, and accepted at end of life elevate the risk for structural inequities and interpersonal trauma. The term *social determinants of comfort* highlights these particular health disparities in the distinctively vulnerable setting of serious illness and end of life.[1]

Thienprayoon and colleagues examined how these domains of quality palliative care apply to pediatric palliative and end-of-life care, from healthcare providers’ perspectives. [4] They drew particular attention to the needs of siblings of children living with serious illness, the financial stress related to caring for a child with serious illness, maximizing school and community engagement opportunities for the child with serious illness, and access to adequate transportation and durable medical equipment to allow maximal participation in social life consistent with child and family goals. Their work anticipated the notion of

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SDOC, which would exist at multiple levels. At the level of the individual child, this may include access to care, a knowledgeable pediatric pharmacy, and recognition of their pain. For the individual parent, it highlights the stress experienced from caregiving, employment, and interacting with healthcare providers. At the level of the family, it highlights how a sibling may serve as caregiver to the seriously ill child or other sibling or how financial stressors may cause discord between family members. At the level of the community, for example, siblings may not be able to access supportive services in schools or health care settings or lack of safe transportation in the community may make attending follow-up appointments difficult. It is evident how these elements affect patients and families in the vignettes above.

Recognizing that SDOC influence differences in access to palliative, hospice, and concurrent hospice care is vital to eliminating health inequities that reinforce social vulnerability and disadvantage.[5] Such recognition is necessary to illumine the barriers that interfere with providing comfort to some patients with serious illness or at end of life, and to pave the way for these barriers to be addressed. Conversely, inattention to the SDOC compounds the vulnerabilities of some patients and families.[6] As such, it exposes them to risk of dire outcomes during end of life and through bereavement and undermines a just and ethical approach to care. While many patients are subject to SDOC, these determinants can be especially significant when a child is at end of life.

Understanding health equity related to pediatric concurrent care, as an example, is important because of the rare and complex nature of terminal illness in childhood. Compared to adults, children tend to have longer disease trajectories that can include prolonged hospitalizations and intensive home-based care. Moreover, children do not have the legal authority to make medical decisions and are especially vulnerable at such a crucial point in their lives. Thus, parents play a vital role in the management of their care while experiencing psychological distress, poor health behaviors, work challenges, and financial hardships that impact the whole family. Symptom assessment and management needs to be tailored to the child's developmental stage; yet, quality-of-care measures are practically nonexistent for pediatric end-of-life care and current adult measures lack a developmental lens. Given the legal and developmental vulnerabilities and the role of the family and other contexts that play a significant role in the lives of children facing terminal illness, pediatric end-of-life care needs to be explored through a social ecological lens to ensure all relevant variables are identified and considered.

The goals of this paper are to 1) describe and articulate the impact of structural and ecological factors on the comfort children and families can attain near the end of life; 2) describe how these factors to support children and families in attaining comfort, and possibly even flourish, at end of life can be addressed; and 3) provide an agenda for research that addresses how palliative care research can advance health equity and how a focus on equity can advance palliative care science. The authors argue that various inequities reinforce social vulnerability and disadvantage throughout the lifespan and can have profound effects for children, particularly children with serious illness or at the end of life. Ethical care for these children at end of life requires recognition of the SDOC.

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Theoretical Framework

Understanding how a child and family are situated ecologically is foundational to comprehending the role of SDOC for children and their families at end of life. Nurses and other professional need to acknowledge the various systems within which the child is nested and how the child and these systems are interrelated. While the family is one system within which the child is nested, the family itself is also nested within various systems and their ability to provide care and comfort to their child and survive their death are influenced by these systems. [7]

An ecological framework enables healthcare professionals to understand, explore, and address the impacts of social determinants of health on the lives of seriously ill youth and their families. Social determinants of health are defined as conditions in a person's environment that influence health which include socioeconomic status, education, neighborhood, physical environment, employment, social supports, and access to care. [8] Social determinants of health can be broadly grouped into five domains, including economic stability; education access and quality; health care access and quality; neighborhood and built environment; and social and community context. Examples from these domains include considerations for safe housing, transportation, violence, racism, discrimination, income, job opportunities, education, literacy, and air/water pollution. Research on the social determinants of health suggest that health and illness often result from social, economic, environmental, and interpersonal factors; arguably these factors can be more important than biological mechanisms for preventing and treating disease.

Addressing the ecological roots of health problems must become part of the process to improve outcomes and promote health equity. As families fulfill their functions to socialize and protect their members, they incorporate and interpret the larger sociocultural and political worlds for their members. Therefore, issues that affect any part of the ecological worlds of individuals can affect the health of families by either providing protection or increasing risk. Although families are important to mitigating risk for their members, they can also be negatively affected by changing social policies and political systems, especially families who are potentially vulnerable. [9]

Similarly, by addressing SDOC health equity is promoted by removing obstacles to comfort, such as by facilitating access to high-quality concurrent hospice care through state Medicaid programs. In a palliative context, "equity" means that that every seriously ill child has a fair opportunity to attain the highest level of well-being possible for them. SDOC are also the conditions and factors in the environments where people live with their illnesses, die from their illnesses, and live as family members and caregivers to those living with serious illnesses. Addressing SDOC contributes to health equity because they can affect a person or family's ability to access resources. It also diminishes health disparities, or avoidable differences in care, such as decreased access to resources, decreased quality of available care, increased negative health outcomes, and increased provision of care that is inconsistent with cultural values and patient/family goals. Disparities can ultimately lead to suffering at end of life. Figure 1 from Healthy People 2020 provides a helpful diagram to illustrate how

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social determinants of health act across a person's context and lifespan, and how they impact outcomes. [10]

Research has shown that identifying and addressing social determinants is vital for improving comfort outcomes for people and populations.[5] In fact, policies that perpetuate inequity, discrepancies in the allocation of social resources, and burdens in the environments in which people live contribute to poor comfort. Awareness of these discrepancies, in turn, highlights systemic barriers to health and the resulting unjust variations in well-being. Moreover, recognition of the SDOC helps contextualize individuals' health choices in their social milieu, thereby highlighting the role that environment plays in determining what comfort-related choices are available for different individuals.[11] Since the health of a population determines its ability to flourish, health inequities threaten all members of society due to the loss of the talents and contributions of those who are directly harmed by them. [5]

Finally, it should be noted that SDOH affect SDOC at multiple levels. As one example, lack of access to preventative and curative health care (SDOH) can lead to diagnosing life-threatening conditions relatively late in their course. Late diagnosis, in turn, can interfere with timely recognition of options, effective means of managing symptoms, and patient/family acceptance that the patient is at end of life – all of which are SDOC.

Analysis

This paper was part of a larger research project examining pediatric end-of-life care with a specific focus on concurrent hospice care. The research team had previously argued that justice requires equitable access to pediatric concurrent hospice care for children with serious illnesses and their families.[12] The team engaged in many discussions regarding results from investigation of administrative pediatric concurrent hospice data with a focus on the medical services provided and wanted to understand the broader bioethics and policy implications of the study findings. Specifically, they wanted to understand which children and families *are and are not* receiving concurrent hospice care, potential barriers to that care, and how barriers at individual, family, healthcare provider, agency, state, regional, and policy levels can impact receipt of quality palliative and end-of-life care.

During one team discussion, a member coined the phrase "social determinants of comfort" to capture the factors that could determine access to, receipt of, and experience with pediatric concurrent hospice care. Comfort care, as part of concurrent care, focuses on the need to relieve suffering, increase one's quality of life, and ensure the person's dying wishes are respected. The concept of "social determinants of comfort" has been introduced and defined in a previous publication. [1] See Figure 2 for a map of the process.

Discussion

Addressing child and family suffering is at the heart of pediatric palliative and end-of-life care. Understanding relationships among SDOC, health equity, and pediatric palliative and end-of-life care remain understudied. Nurses and other professionals need to address this gap because SDOC are recognized as major influences on the health of individuals, families, and populations. Evidence suggests that social determinants, including socioeconomic

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status, education, neighborhood, physical environment, employment, social supports, and access to care, may impact the palliative, end-of-life, and bereavement experiences of children and their families. Thus, a better understanding of this intersection from a multilevel perspective is needed.

The sociocultural context is composed of the culture within which children and families live and grow, the communities in which they live, and the institutions from which they receive care. For children receiving palliative, end-of-life, or concurrent hospice care and their families, the community and environmental context is comprised of the places where these children receive care and die and where their families live, work, and render care. This can include the built environment, such as city landscapes, architecture, and the quality of air and water. For children with serious illnesses receiving concurrent hospice care, living in a rural region can impact access to tertiary or quaternary care centers or pediatric home hospice providers.[13] Additionally, children living in less resourced areas may have less access to home or community-based care.[14]

End-of-life care programs (i.e., palliative, hospice, concurrent hospice care) in the United States have grown significantly in the past decade.[15] Although many patients experiencing serious illness at end of life are able to receive excellent care for their symptoms through these programs, many still suffer because they do not have access to patient- and family-centered comprehensive care.[16,17] Svynarenko and Lindley [13] highlight the intersection of physical environment and socioeconomic status as a determinant of comfort in their description of rural hospice care. There was a negative relationship between residing in a rural area and income. Rural hospices were more likely to be present in the Midwest and South. Laird and colleagues describe presence of guidelines for enacting section 2302, the concurrent hospice care provision, of the Affordable Care Act (ACA).[18] This work is helpful in understanding access to resources that may be different because of variations in state-level implementation of concurrent hospice care guidelines. They found 19 states provided no guidelines for implementation of this benefit.

Palliative, hospice, and concurrent hospice care focus on quality of life for patients with serious or complex illness. They often use multi-disciplinary approaches to alleviate distressing physical symptoms, provide emotional support, extend life when possible, and relieve meaningless suffering. Care focuses on respect for patients' values, culture, and religious/existential beliefs, as well as attention to their loved ones' needs during illness, end of life, and the grieving that follows.[19] However, multiple factors contribute to what measures are *available*, *offered*, and *accepted* by patients and their families. Reimbursement, provider knowledge, culture, and geography are key drivers. The fact that wide variations in comfort exist at such a vulnerable time in patients' and families' lives is an instance of significant social injustice, and warrants action at multiple levels of health care delivery.

Bem and Small provide a helpful way of discerning the impact of social determinants on comfort. [7] Professionals must attend to the child's physical health status and functional status.[20] Supporting this would include the intensive symptom management provided through concurrent hospice care, access to home-based technology, and care coordination. Attention must also be paid to family caregivers, who provide the bulk of supportive care.

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This would include caregiver physical and mental health screening; referral for community support or treatment; and provision of psychosocial support by a member of the teams caring for the child. Mental health can be supported through emphasizing a health and strengths approach versus a pathology or deficit-based approach. Early evidence to date that suggests a significant portion of children and adolescents receiving concurrent hospice care for a serious life-limiting illness also have mental health diagnoses.[21] Thus, concurrent hospice care is important for ensuring these children have skilled and consistent care from mental health providers that does not end with initiation of hospice care.

While traditionally considered as conditions of health, social determinants are also critical conditions of comfort at end of life. End-of-life comfort varies by patient- and family-based features, such as race/ethnicity,[22] culture, [17], and socioeconomic status [23]; provider-based features, such as communication skills and familiarity with comfort care;[24] and hospital-based features,[16] such as region, urban density, and tax status. Furthermore, homeless patients at end of life generally do not have access to comfort measures such as medications, treatments, or therapies because of their lack of access to health care, insurance, and social support. [25] It is particularly poignant that these disparities occur when patients are distinctively vulnerable due to serious illness or at end of life.

SDOC are illuminated in glaring and immediate ways when considered in the context of pediatric palliative and end-of-life care. Attention to this intersection is the foundation for socially-just care and an avenue to understand upstream and downstream factors that impact access to high-quality palliative care. Awareness of how *comfort at the end of a child's life can be socially determined* informs a holistic approach to health care delivery that creates a bridge across the multiple levels that impact child and family heath.

Implications

A Call to Disambiguate and Act

Current research indicates that utilization of measures to promote comfort at end of life varies by several factors, including what is available, what is offered, and what is desired by the patient and family (Table 1). A related variable, more difficult to describe and to measure, is *how* comfort measures are offered, and how offers or recommendations for comfort measures are understood by patients and families. Here, this variable is referred to as *accepted.*

Disambiguation may be difficult. For example, it is not clear how often the request for aggressive care (or disinclination towards comfort measures) is a genuine preference to extend life even at much lower quality as opposed to a family's hope that by asking for more than they want, they will get what they need. Rejection of comfort-related measures may reflect cultural or religious beliefs (e.g., that life should be extended out of respect for the creator, that suffering is to be borne graciously, etc.) or may reflect a fear that the offer of "comfort measures" signifies the health care team's lack of interest in helping the patient recover. However, these very different perspectives require different approaches to be able to meet the needs of patients and their families. Moreover, more than one of these variables can be operating within the same patient and family.

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Available.

The rural area where they live has a strong community, but there are few resources there to assist with Kayla's needs. Many families, like Kayla's in the case above, are unable to access palliative measures because they are not available in their region. What comfort measures are available to patients and families can vary for several reasons. In some cases, needed resources simply do not exist in a geographic region or within the health system where a child receives care. At the Center to Advance Palliative Care, access to end-of-life care is described as "an accident of geography."[16] An example of this barrier is families' inability to access narcotics from local pharmacies because of no supply, inability to cover copayment, or insurance denial. In others, insurance or other financial barriers can keep children and families from accessing resources they need. Especially vulnerable are undocumented patients and low-income patients in states that have not opted to expand Medicaid.[23] For some children, what is available is limited by the family's social resources. For example, a child who does not have family members who can provide the level of care required would not be able to remain at home for end-of-life care.

Offered.

What is offered to patients and families can vary as well. Health care providers' awareness of what resources are available may be the simplest reason why some children are offered resources and others are not. Even if something is a perfect fit, a provider is not able to offer it if she does not know about it. Moreover, if providers are not in the habit of referring families for particular palliative resources or are not familiar with concurrent care, they will make these recommendations less frequently.

Additionally, there may be situations in which health care providers have ideological reasons they do not investigate or offer palliative resources. Many providers refer to palliative care much later than is ideal because they "don't believe we're there yet." Others are uncomfortable with end-of-life issues and may have misconceptions about hospice. Finally, some providers may not think to offer resources to some families due to their untested beliefs about those families (e.g., unconscious bias). Additional research is needed to learn what comfort measures are offered, to whom, and by whom.

"We need to have hope," her oncologist said. "And the family needs us to give them hope." In the case of Madison, physicians are unwilling to acknowledge that a cure is unlikely. The patient's comfort is not being addressed adequately in part because her providers are not comfortable offering palliative measures.

Accepted.

"I don't need to move heaven and earth to come in and listen to someone tell me to give up on my son." Emma, mother of baby Tyler, feels disrespected. She may have an incomplete understanding of her son's prognosis, likely owing to several factors that may amplify one another. Avoiding the NICU to avoid feeling judged, she may associate hearing from providers with catastrophic news and being pushed to "give up". Providers who are frustrated with her absence and her baby's suffering may be at a loss for how to connect with her, literally and figuratively.

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Comfort-related measures that are available and desired may not be accepted by families because of communication issues when they were offered. Broadly, some of these variables are primarily provider-centered and others are primarily family-centered. Variables that may contribute to whether measures are accepted include timing, trust, relationship between family and provider, gaps in cultural sensitivity of health care providers, and health literacy of families. More knowledge about these variations allows for better systems with trained individuals to provide compassionate and equitable comfort to dying patients and the families caring for them.

Desired.

The fact that there are wide variations in what comfort measures are available and what measures are offered to whom is a breach of justice. However, it should be recognized that not all differences are instances of inequity. Some patients and families may not utilize comfort measures that are available and have been offered – and offered in a clear, culturally-sensitive manner – simply because they are not in line with their values and goals.

Conclusion

"Social determinants of comfort" is an important concept because it articulates the complex, comfort-related services children, adolescents, and young adults need across settings and across time.[12,26] In highlighting the intersection of ecologies and hospice, palliative, and concurrent care, this concept begins to elucidate the struggles youth and families contend with and helps professionals understand the cascading effect of health care policy and systems on health equity.

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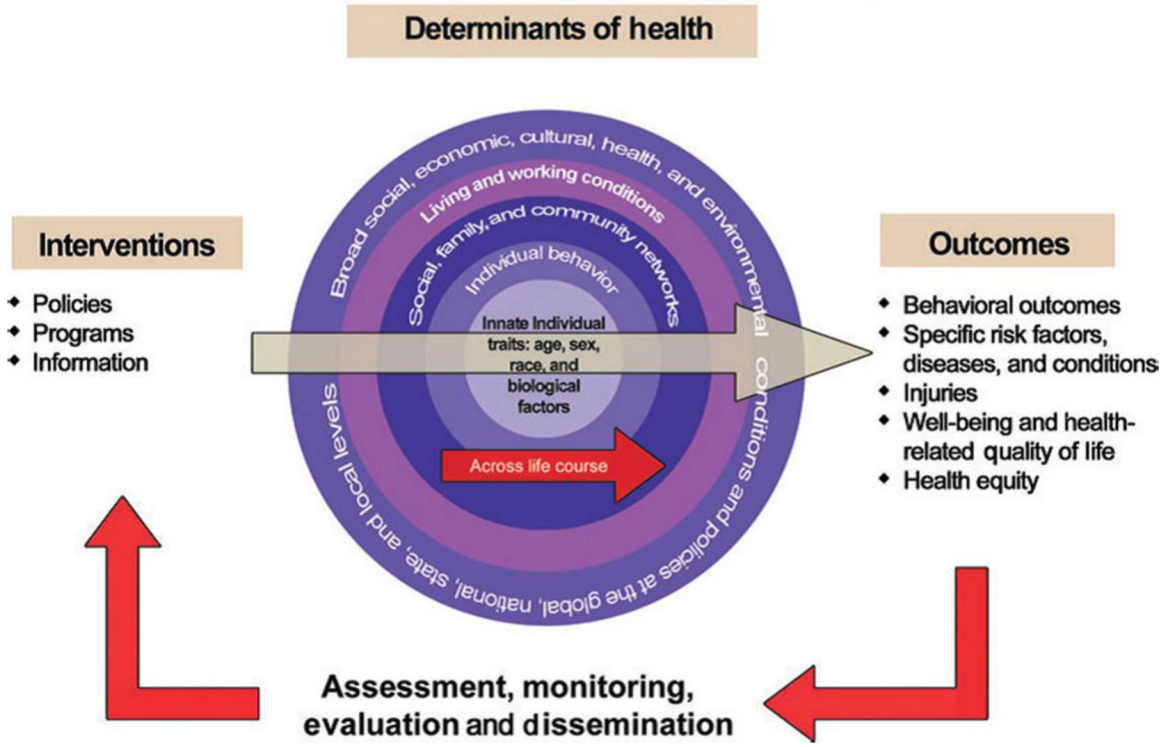


Figure 1: Action Model to Achieve Healthy People 2020 Overarching Goals
From: U.S. Department of Health and Human Services Secretary's Advisory Committee on Health Promotion and Disease Prevention Objectives for 2020, p. 22.[10]

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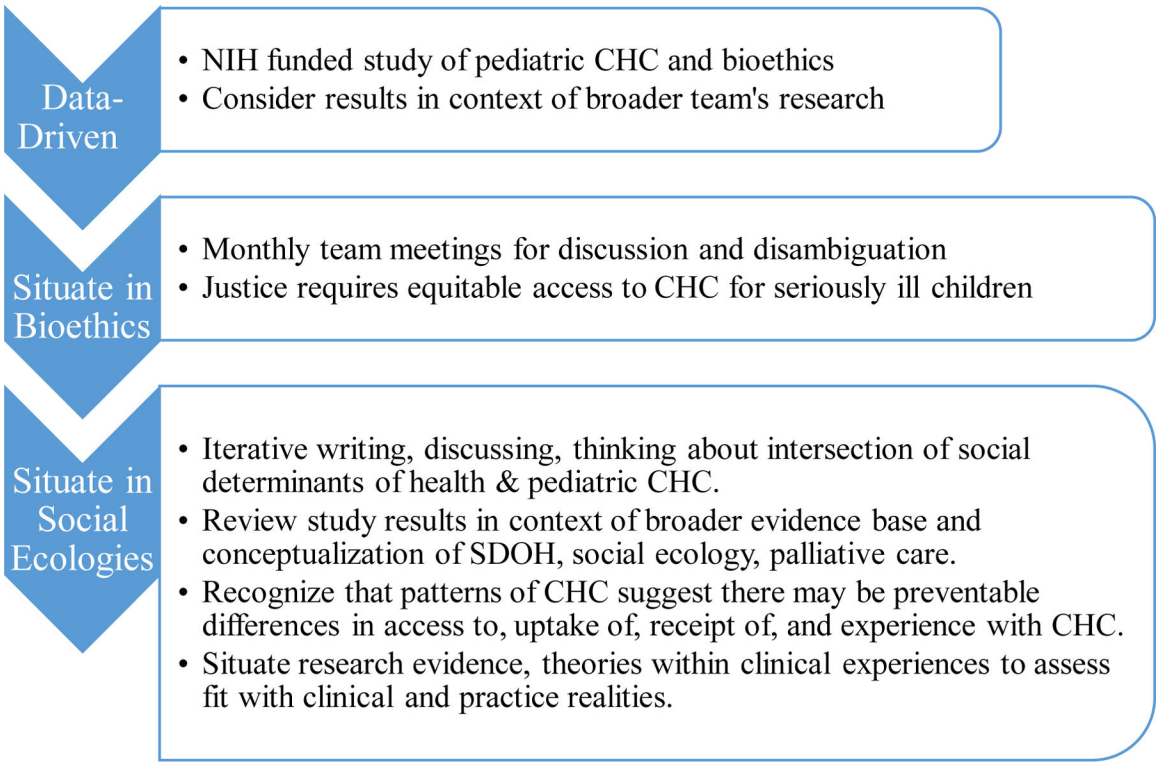


Figure 2.
Team process for concept development

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Table 1.

Descriptions of available, offered, desired, & accepted

Available	Offered	Accepted	Desired
Resources simply do not exist in a geographic region or within the health system where a child receives care	Health care providers' awareness of available resources, familiarity with comfort care, hospice, concurrent care	Family's level of trust/distrust of health care system and/or health care providers; fear of being denied needed treatment. [17]	Cultural value of accepting suffering as part of life/part of God's plan [17]
Insurance barriers	Health care providers' awareness (discernment) that patient could benefit from comfort measures	Cultural competence and/or communication skills of providers	Personal values and goals
Family's financial resources	Health care providers' comfort level with comfort measures	Language barriers, particularly for recent immigrants and families [17]	Cultural prohibition of talking about death [17]
Limitations of the home environment &/or family's ability to provide care	Health care providers' untested beliefs about family	Family's level of understanding and/or acceptance of disease progression	Cultural value of accepting the burden of caregiving [17]