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Identity and Wisdom as Elements of a Spirituality of Hope among Children with End-stage Renal Disease

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The Pauline literature of the New Testament presents hope as a constitutive element of the abundant life (John 10:10) that is central to Christian spiritualities, and recent theologies have emphasized the role of hope in Christian theologies, especially in relation to the doctrine of eschatology.[1] These developments have been enriched by attention to faith practices that contribute to hopefulness in Christian contexts; as pastoral theologian Duane Bidwell[2] notes, an interdisciplinary group of theologians—including Donald Capps, Russell Herbert (2006), Flora A. Keshgegian (2006), Andrew D. Lester (1995), and Ellen Ott Marshall (2006)—has recently proposed theological and pastoral practices that can nurture hope as a spiritual resource.[3] This literature primarily addresses adult experience through a Christian existential lens; its emphasis on the future and its eschatological assumptions may prevent it from being useful for the nurture of hope among children.[4] Yet no theologians have engaged children's own accounts of hopefulness or explored the practices that children themselves say nourish hope.[5]

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[1] See, for example, 1 Cor. 13:13, Rom. 5:2 and 8:24, Heb. 10:23, Eph. 1:18 and 4:4, Col. 1:27, Titus 2:13, 1 Thess. 4:13, 1 John 3:2, 1 Pet. 1:3 and 3:15, and 1 Tim. 1:1.

[2] Duane R. Bidwell, "Eschatology and Childhood Hope: Reflections from Work in Progress," *The Journal of Pastoral Theology* 20/2 (2010): 109-27.

[3] Donald Capps, *Agents of Hope: A Pastoral Psychology* (Minneapolis: Fortress Press, 1995); Russell Herbert, *Living Hope: A Practical Theology of Hope for the Dying* (Peterborough, Great Britain: Epworth Press, 2006); Flora A. Keshgegian, *Time for Hope: Practices for Living in Today's World* (New York: Continuum, 2006); Andrew D. Lester, *Hope in Pastoral Care and Counseling* (Louisville: Westminster John Knox Press, 1995); Ellen Ott Marshall, *Though the Fig Tree Does Not Blossom: Toward a Responsible Theology of Christian Hope* (Nashville: Abingdon Press, 2006). Contemporary theological interest in "Christian hope," especially in pastoral theology, may be traced to Jürgen Moltmann's early work, *Theology of Hope*. Moltmann was influenced by the Marxist-Existentialist philosopher Ernst Bloch, who also informed Latin American liberation theologies. See *Jürgen Moltmann, Theology of Hope: On the Ground and the Implications of a Christian Eschatology*, trans. James W. Leitch (New York: Harper and Row, 1967).

[4] Duane R. Bidwell and Donald L. Batisky, "Abundance in Finitude: An Exploratory Study of Children's Accounts of Hope in Chronic Illness," *The Journal of Pastoral Theology* 19/1 (2009): 38-59.

[5] Vickie E. Lake, "Children's Stories of Hope: Moving Toward an Expanded Understanding of the World Children Live In," *Early Child Development and Care* 173/5 (October 2003): 509-518.
In general, psychologists, nurses and early-childhood specialists have done a better job than theologians of attending to children's experiences of hope, but they primarily—although not exclusively—propose non-contextual models of childhood hopefulness focused on cognition and emotion. These models have limited utility for contemporary theology.

This article describes and reflects on a preliminary theological-spiritual understanding of hope that is grounded in, and accountable to, the experiences of particular children living with end-stage renal disease. Our understanding emerges from a grounded-theory study of hope among chronically ill children. (A thorough description of methodology appears elsewhere).[6] As qualitative research, these findings should not be generalized beyond the particular healthcare setting where the research occurred.

But this model might have a pragmatic, heuristic value for conversations about hope as a spiritual resource among children.[7] For example, it resonates with a broader framework for understanding childhood and adolescent spirituality that has emerged from a large-scale empirical study of children across the world and from different faith traditions.[8] Our model might also inform an emerging biomedical and psychosocial consensus that chronic, life-threatening illness is "fundamentally a spiritual crisis"[9] marked by the central concerns of making meaning, finding hope, and facing death.[10]

We use the terms "spiritual" and "spirituality" here to refer to a lived pattern of response to a dynamic, ultimate reality—one that approaches human beings from beyond a transcendent

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[6] Bidwell and Batisky, "Abundance in Finitude," 39-40.

[7] Bidwell and Batisky, "Abundance in Finitude," 39.

[8] Eugene C. Roehlkepartain, Peter L. Benson, Peter C. Scales, Lisa Kimball, and Pamela Ebstyne King, *With Their Own Voices: A Global Exploration of How Today's Young People Experience and Think About Spiritual Development* (Minneapolis: Search Institute Center for Spiritual Development in Childhood and Adolescence, 2008).

[9] Kenneth J. Doka, *Counseling Individuals with Life-threatening Illness* (New York: Springer Publishing Co., 2009), 163.

[10] Kenneth J. Doka, *Living with Life-threatening Illness: A Guide for Patients, Their Families, and Caregivers* (San Francisco: Jossey-Bass Publishers, 1993), 160-161.

horizon and manifests through the mundane and material world. Human experiences of the ultimate—which for Christians is the liberating God revealed by Jesus—occur only through social and cultural realities.[11] Our usage of the terms follows that of spirituality scholar Joseph D. Driskill, for whom spirituality is a lived experience of faith "concerned with the community that shapes and celebrates [it], the spiritual practices which sustain it, and the moral life which embodies it."[12] Thus, spirituality refers to a socio-cultural/existential phenomenon and a dimension of experience recognized in many Eastern and Western cultures. As scholars, we approach this phenomenon from a descriptive-critical rather than prescriptive-normative stance, [13] which entails a critical appraisal of a person's accounts of spiritual experiences. The word "resource" here denotes a wellspring or site of understanding, energy, and consolation that can enhance people's natural capacities (to endure suffering, for example) or provide the power and resources to accomplish what people could not achieve on their own.

Contextual Factors

The accounts of our research partners—seven girls and five boys ranging from 9 to19 years—lead us to envision hope as a contextual spiritual resource that manifests through the interplay of social processes, an individual's internalized resources, and a transcendent presence.

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[11] See Dwight N. Hopkins, *Being Human: Race, Culture, and Religion* (Minneapolis: Fortress Press, 2005).

[12] Joseph D. Driskill, "Spirituality and the Formation of Pastoral Counselors," in *The Formation of Pastoral Counselors: Challenges and Opportunities*, eds. Duane R. Bidwell and Joretta L. Marshall (New York: Routledge, 2007), 74.

[13] Sandra M. Schneiders, "Spirituality in the Academy," *Theological Studies* 50/4 (December 1989): 676-697.

Like all children, our research partners live in a paradox of strengths and vulnerabilities, a childhood reality that theologian David Jensen calls “graced vulnerability.”[14] As we have written elsewhere, three contextual factors shape the strengths and vulnerabilities of our research partners: end-stage renal disease itself, the interdisciplinary treatment team, and experiences of suffering.[15] These contextual factors particularly shape the ways in which our research partners understand hope.

End-stage Renal Disease

End-stage renal disease is an incurable and potentially fatal chronic illness that requires medical intervention to replace some functions of the kidneys so that the body can be cleansed of excessive toxins. The best treatment is a kidney transplant, but a transplant is not a cure; on average, a transplanted kidney functions well for only 15 years. The disease and its treatment can also create additional long-term health concerns, especially in the cardiovascular system.[16]

Interdisciplinary Team

These concerns can be managed through an interdisciplinary treatment team that serves as an ongoing web of supportive resources for children and parents. The team also constitutes a particular culture or community into which patients and families are welcomed. Through

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[14] Marsha J. Bunge, “Reexamining Children’s Paradoxical Strengths and Vulnerabilities: Biblical and Theological Perspectives” (keynote address, Third Triennial Children’s Spirituality Conference, Concordia University, River Forest, IL, June 14-17, 2009); David H. Jensen, *Graced Vulnerability: A Theology of Childhood* (Cleveland: The Pilgrim Press, 2005).

[15] For fuller descriptions of these contextual factors, see Bidwell and Batisky, “Abundance in Finitude;” and Bidwell, “Eschatology and Childhood Hope.”

[16] U.S. Renal Data System, *USRDS 2008 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States* (Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2008).

intentional and unintentional practices, team members create a community of hope and socialize patients and their families into that community. The team's expectation that patients of all ages can and will participate in managing the disease contributes to the hopefulness identified by our research partners.

Suffering

The most influential contextual factor for our research partners is suffering—physical, psychosocial, and intra-psychic. Psychosocial and intra-psychic sufferings were mentioned twice as often as physical suffering. While coping with chronic physical pain, our research partners also experience disrupted peer relationships, restriction of normal activities, awareness of being different from other children, and a sense of losing a part of themselves. Intra-psychic suffering manifests primarily as fear, loss, and worry.

The Multifaceted Nature of Hope

Shaped by these contextual factors, our research partners provided descriptions of hope that have a richness and depth missing from the primarily existential understandings of recent pastoral theologies, the cognitive model privileged by psychology, and the emotional understanding central to the literature of nursing.[17]

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[17] See, for example, C. R. Snyder, *The Psychology of Hope: You Can Get There from Here* (New York: Free Press, 1994); C. R. Snyder, "Measuring Hope in Children," in *What Do Children Need to Flourish: Conceptualizing and Measuring Indicators of PositiveDdevelopment*, eds. Kristin Anderson Moore and Laura H. Lippman (New York: Springer Science and Business Media, 2005); Thomas W. Connelly Jr., "Family Functioning and Hope in Children with Juvenile Rheumatoid Arthritis," *MCN: The American Journal of Maternal/Child Nursing* 30/4 (2005): 245-250; Carol J. Farran, Kaye A. Herth, and Judith M. Popovich. *Hope and Hopelessness: Critical Clinical Constructs* (Thousand Oaks, CA: Sage Publications, 1995).

Hope does have existential, cognitive and emotional dimensions for these children. But they also experience it as participatory, relational, kinesthetic, perceptual, and—perhaps most significantly—conative. The will—that is, the ability to choose—has a prominent place in their accounts of hope; hope is not a passive experience for them but an active decision that often precedes or informs other dimensions of hope. This finding is consistent with research that suggests children perceive an element of choice in their spiritual development.[18] For example, Bradley, a 15-year-old dialysis patient, describes the relationship between end-stage renal disease and hope:

> It ain't a part of me; I'm a part of it. Well, it is a part of me, but it doesn't have control over me. I have control of it. . . . I don't let pain or my disease take control over me. I know there's something better; I know there's something else rather than just letting it come over me. . . . I just live day by day, year by year. I don't think about the now; I think about the future—how I can do stuff . . . how I can give back. . . . I believe there is hope.[19]

Our research partners often describe an immediate manifestation of hope—an awareness of the abundance that surrounds them day by day—represented primarily by supportive family, friends, and members of the interdisciplinary team. Eighteen-year-old Tom is a transplant recipient:

> Hope is keeping up, looking forward, being happy and joyful while you still can. [It is] looking to the bright side of life and enjoying life and your family—all the good things in

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[18] Roehlkepartain, et. al., *With Their Own Voices*, 11.

[19] Bidwell and Batisky, "Abundance in Finitude," 43.

> life. . . . Just hanging out with my friends and family and looking to the bright side of life—all the good things in life.[20]

Stated in these terms, hope seems to become an aspect of realized or sapiential eschatology,[21] what pastoral theologian Peggy Way calls the "ordinary grace" that places "ultimacy and immediacy in the same sentence."[22]

For our research partners, hope often entails being aware, in the moment, of the fullness of life, relationships, and caring community amidst the finitude of disease. This understanding resonates with the three elements of children's spirituality—awareness or awakening, interconnecting and belonging, and living an integrated life—proposed by the Center for Spiritual Development in Childhood and Adolescence, based on a world-wide empirical study.[23]

Pathways to Hope

In the accounts of our research partners, we identified five pathways to hope: maintaining identity, real/izing connections, claiming power, attending to God, and learning wisdom. (See Fig. 1) We have written previously about the pathways of "real/izing connections" and "attending to God";[24] this article focuses on "maintaining identity" and "learning wisdom," providing a description of each pathway and identifying practices that promote them.

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[20] Bidwell and Batisky, "Abundance in Finitude," 44.

[21] Bidwell, "Eschatology and Childhood Hope," 109-27.

[22] Peggy Way, *Created by God: Pastoral Care for all God's People* (St. Louis: Chalice Press, 2005), 41-42.

[23] Roehlkepartain, et. al., *With Their Own Voices*, 40-47.

[24] See Bidwell and Batisky, "Abundance in Finitude," 45-49.

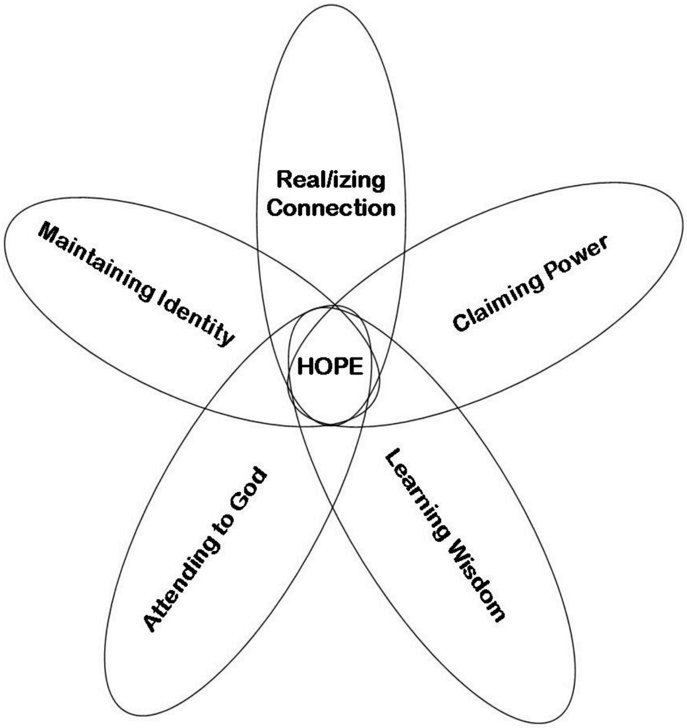

Fig. 1: Pathways to Hope: A Preliminary Theological Model

In the preliminary model, the greater the overlap between pathways, the more likely hope is to be present for a particular child. Interventions to nurture hope can focus on (a) strengthening pathways already apparent in a child's life and (b) activating pathways that seem weak or absent. We suspect that the more pathways "activated" for a particular child, the more hope that child feels.

Maintaining identity reflects the desire and efforts of children with end-stage renal disease to continue to participate in the activities and relationships that shaped their sense of self prior to diagnosis and treatment. This facet of hopefulness is primarily performative and agential;

it focuses on what a child can do despite limitations created by the disease and treatment. Children with the disease are keenly aware of being different from healthy peers; behaviors that maintain pre-disease identities allow them to remain "normal" (or to become "more normal," in the words of one research partner) despite the illness. Internalized norms about being a child (established through particular socio-cultural contexts) are a motivation to participate in treatment and can become a source of tension when the disease creates barriers to "being normal." Some children also discover new and positive facets of identity as they cope with the disease, seeking to integrate these new self understandings into their pre-disease identities. One way that children maintain identity in the midst of treatment is by externalizing end-stage renal disease, speaking of it as an entity and force separate from and alien to themselves.

Real/izing connections weaves children who have end-stage renal disease into a community of mutuality and trust that assures them that they are not alone in living with the illness. This facet of hopefulness is primarily relational; by making connections to others "real," children participate in the creation of social capital that provides resources for coping with the psychosocial, spiritual, and intra-psychic aspects of the disease. While relationships with members of the interdisciplinary treatment team are primary in this process, the illness also leads many children to develop multifaceted connections to a broader community. These connections can be formal or informal. Children especially value connections to other children and adults living with kidney disease. Connections to others are made real through conversation, visitation, consultation, and participation in daily activities; in the process, children receive (and often give) guidance, empowerment, reassurance and encouragement. Some relationships offer children a broader vision of future possibilities despite the ongoing effects of kidney disease. Social artifacts generated through these relationships can be internalized to increase agency and clarify identity in the midst of the disease; thus, relationality is constitutive element of claiming power and maintaining identity, two other pathways to hope.

Claiming power allows children with end-stage renal disease to take an active role in treatment by setting goals, advocating for themselves, and monitoring and maintaining their own health. This facet of hopefulness is primarily agential; it focuses on children's abilities to influence outcomes, access resources, and participate meaningfully as a member of the interdisciplinary team. Children claim power by refusing to be an object that passively experiences the disease and its treatment; instead, they assert themselves as subjects in relation to other members of the interdisciplinary team and in relation to the effects of the disease. For some children, claiming power includes identifying and enacting strategies to control anxiety as a means of resisting the intra-psychic suffering that can accompany the illness. By acting to claim power in relationship to the disease, children can influence health outcomes and thereby obtain more freedom from the limitations imposed by the disease and its treatment.

Attending to God provides spiritual consolation to children with end-stage renal disease by assuring them that God is present in their suffering and participates in the treatment process. This facet of hope is primarily relational and sapiential; it is activated through religious and spiritual practices such as prayer, worship, visitation, blessing, and the reading of scripture. Some children invoke a family wisdom figure, such as a grandparent, as a spiritual guide to help them attend to God. Children with end-stage renal disease tend toward an instrumental understanding of religious resources (using prayer, for example, to relieve anxiety during dialysis), but speak intimately and personally of God's availability and presence with them in the midst of illness. Prayer is the primary way that these children connect to God.

Learning wisdom allows children with end-stage renal disease to integrate technical information from the interdisciplinary team with a noetic assurance about their own well-being to relieve immediate intra-psychic and spiritual suffering, enhance agency, and generate possibilities for the future. This facet of hopefulness is agential, relational, and resource-oriented; it can also have a transpersonal dimension. Children seem unaware of pre-diagnosis resources and knowledge that help them cope with kidney disease; they perceive wisdom as evolving primarily from the team's expertise and secondarily from the child's own transpersonal awareness of a positive personal future. Among older children whose diagnosis occurred when they were young, this integrative awareness can create a vocational desire to use their experiential wisdom to benefit others. In this way, learning wisdom moves children beyond egoic concern for their own well-being to a generative focus on the well-being of other children living with chronic illness. Finding ways to "give back" what they have received and to activate a special, noetic connection with caregivers and other chronically ill patients are significant ways that these children make meaning of their illness.

Maintaining Identity

Describing the Pathway

As a pathway toward hope, "maintaining identity" reflects children's desires and efforts to "be normal"—or, in the words of 14-year-old Sally, who lives with a transplanted kidney, to be "more normal." Most often, "being (more) normal" means to participate again or more frequently in the activities and relationships that shaped identity prior to diagnosis and treatment. Thirteen-year-old Gina, a transplant recipient, talks about it this way:

> I thought with all this, you know, in about ten or twelve years, I would still have to be taking medication—extra medication or something—but instead they had to come out with dialysis; then I had to have a tube put in; so then I didn't have much hope. Then my parents were like, "Oh, no, you'll get better. You are going to be able to go out and play and hang out with friends. Don't just focus on that one little thing, getting through all this." Then I will be able to have most of my normal life . . . just to be able not to be getting hooked up [to dialysis] every night; then I could, like, stay over at a friend's house and stuff. Be a normal teenager.

Children with end-stage renal disease are keenly aware of being different from healthy peers. Their bodies and activities remind them daily of their differences, and any practice that encourages them to remember and rehearse who they are apart from the diagnosis seems to nurture this pathway to hope. This facet of hopefulness is primarily performative and agential; it focuses on what a child can *do* despite limitations created by the disease and its treatment. Yet it can also involve normalizing the ways the disease shapes a child's life. For example, our research partners delight in Kidney Kamp, an annual, week-long overnight camp organized by members of the interdisciplinary team. Camp, says fifteen-year-old William, provides an opportunity to be with peers:

> who had the same problem as you and don't make fun of each other about it. . . . They don't sit and stare at you and point and laugh and whisper to each other about you. They

> just ask you when you started dialysis, how long you had been on dialysis. Sometimes they show each other scars or [ask] about what point that they go through and how they got started on dialysis, when they got the transplant and how long they had it. . . . like it is normal for kids. . . . When I first started, [I] thought it only happened in grownups and older people—like I didn't think it happened to kids. . . . It is kind of a relief when you are around people . . . , [and] everybody has the same thing. It is not that they can't make fun of each other; it is just like they don't bother to make fun of each other because it is not funny. . . . They think I am the same, normal kid.

Some children, of course, discover positive, new facets of identity as they cope with the disease; the pathway of maintaining identity includes efforts to integrate these insights into their pre-disease identities. The practices of the interdisciplinary team help make this possible.

Practices that Maintain Identity

A primary practice that helps children maintain identity and integrate new insights in the midst of treatment is, in the language of narrative psychotherapy and pastoral counseling, the "externalization" of end-stage renal disease. Children speak of the disease as an entity and force separate from and somewhat alien to themselves, as something they have a relationship with rather than as something they "are." Bradley, a 15-year-old dialysis patient, says:

> It ain't a part of me. I'm a part of it. It is a part of me . . . but it doesn't have control over me. I have control of it. . . . I don't let pain or my disease take control over me. I know there's something better. I know there's something else rather than just letting it come over me.

When 13-year-old Gina reflects on the relationship between hope and end-stage renal disease, she immediately externalizes the illness: "It's just pulling you back," she says. "You go forward."

Members of the interdisciplinary team can use externalizing language intentionally to help children maintain pre-diagnosis identities and strengthen a sense of agency is relation to the disease. But there is a simpler practice as well: Becoming curious about, and helping re-member, children's lives outside the dialysis unit and transplant clinic. Our research partners emphasized that their hope is nurtured most by the ways that nurses, doctors, and other members of the interdisciplinary team ask informally about friends, family, school, vacation, and weekend plans. Such conversations are not focused on gathering information for medical purposes, but on relationships and day-to-day living in the community of the dialysis unit and transplant clinic.

The concept of re-membering has a rich history in the Christian traditions of pastoral and spiritual care, but here we are using the term as employed in the traditions of narrative psychotherapy and pastoral counseling. For narrative practitioners, re-membering is short-hand for helping a person identify and enrich relationships with people they want on their personal "teams"—people who are supportive, wise and bring strength for positive change. Re-membering conversations contribute at least two strategies for our research partners. First, they distract children from the immediate medical context, re-focusing them on their identities and daily lives apart from end-stage renal disease. Second, they communicate the team's belief that a child has a present and future that include but are broader than the disease. Both effects, our research partners say, nurture hope by helping them maintain their pre-disease identities.

Learning Wisdom

Describing the Pathway

Even as they maintain pre-disease identities, our research partners encounter and integrate new types of knowledge that contribute to a hopeful stance by expanding and enriching their understandings of self and world. We call this knowledge-based pathway "learning wisdom." The process can move beyond cognitive and content-oriented knowing to encompass a greater awareness of non-empirical realities that shape a child's experience with the disease. When our research partners talk about this process, they describe two types of wisdom: First, a pragmatic, medical wisdom that develops as they integrate technical information from the interdisciplinary team with a noetic assurance of their own well-being. This type of wisdom seems to relieve immediate intra-psychic and spiritual suffering, enhance agency, and generate possibilities for the future. The second is an altruistic wisdom expressed as special knowledge or responsibility, including a sense of "connection" with other ill children; sometimes, this altruistic wisdom is expressed in transpersonal terms, and almost always in terms of career and vocation.

These two types of wisdom seem to be sequential. Our research partners first develop a pragmatic (or "practical") wisdom focused on health skills and medical information; some go on to develop an altruistic wisdom motivated by gratitude and focused on their sense of connection with other suffering people. Thus, learning wisdom as a pathway to hope is agential, relational, and resource-oriented; and for children who actively engage the pathway of "attending to God," it can also be transpersonal.

All children have, at the point of diagnosis, existing resources and knowledge that help them cope with kidney disease. But our research partners seem either unaware of or unimpressed by their prior resources. Instead, they perceive wisdom as evolving primarily from the team's expertise and secondarily from a transpersonal awareness of a positive personal future. The team's contribution consists primarily of educating children so that they can understand their experiences and claim power in relation to the disease. For example, Suzy, an 18-year-old diagnosed at infancy, talk about her transition to dialysis as an adolescent:

> It was terrifying because I did not really know much about [dialysis] until they explained it to me. . . . They told me how it worked, and what it can do for me and stuff like that . . . the parts of the machine, and what they do. . . . Then they showed me some doll that had the dialysis catheter in it. . . . When they explained it to me, it actually made me feel better. It did not seem as scary after they told me what they had to do and all that, to put the catheter in and stuff. . . . I guess it made me have more hope . . . .

In addition to teaching how dialysis can "take out the toxins and stuff" (as 13-year-old Gina describes it), the team also teaches necessary health-care skills. Fourteen-year-old Sally named this didactic function as the most important thing that a new team member could do to nurture hope:

> Give the patient all the information and all the guidance that they need for after the transplant and before the transplant. Just tell them what to expect and teach yourself what they should expect. . . . Just give them the skills to do it. Yeah, give them the skills.

This sort of education, she says, helps children have:

> more maturity and more confidence. The more maturity is because, like, you've been through, like, a lot, and you're more confident because you know, like, everything is going to be OK. . . . Like if the doctor tells you that you have to start doing something, or

> you, like, have to change medications or doses . . . it's like, OK, and then you have to like, mature and stand up and do it to make yourself better.

Some older children diagnosed at a young age also develop a type of integrative wisdom that manifests as a desire to draw on their experiences to benefit others medically and psychosocially, which pastor and death educator Kenneth J. Doka notes is a common phenomenon among patients with life-threatening illnesses.[25] Many of our research partners want to become pediatric doctors or nurses. It is at this point that learning wisdom moves beyond egoic concern for a child's own well-being to a generative, altruistic focus on the well-being of other children living with chronic illness. Inspired by gratitude for what they have received from the team, our research partners seek to "give back" to others. Bradley, the 15-year-old awaiting a transplant, said, "In a way, it's kind of like karma; because the hospital's given to me, and I want to try to give back. . . . I know they've done a lot for me—everybody here has—which I really appreciate."

Our research partners also talk about a special, noetic and empathic connection with caregivers and other chronically ill patients—an altruistic wisdom that provides a significant way of making meaning of illness. Fourteen-year-old Rob, who received a transplant eighteen months before our conversation, put it this way:

> I felt like I needed to survive to help other people. . . . I know how they feel when they're sick and stuff. So that's the connection between us and other people—of what pain is and stuff. So. That helps me a whole lot. . . . Some people don't understand, you know; you say it, but you might not really know, you know—so: When I say it, you know, I really mean it—so that might give that person a big, you know, joy . . . .

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[25] See Doka, *Counseling Individuals*.

Likewise, 14-year-old Sally wants to become a nurse because the illness has given her a special empathy and gift for understanding human suffering:

> I just want to, like—if anybody has questions, then, yeah, I'll answer them, because I have been there. And, like, most of the nurses and doctors haven't been there, so . . . just saying, "I know it hurts" and being truthful about it. . . . Like, I could say I know what you're going through and like, mean it, instead of just those doctors saying, "I know it hurts" or whatever. I could say I know it hurts . . . I'd have a personal, like, I already went through it. . . . They know somebody there actually knows what they're going through, and they can have somebody to talk to . . . .

Some research partners do not simply imagine a future where they "give back," but already take an active role in mentoring newly diagnosed children. When 15-year-old William began dialysis, for example, he suffered acute anxiety that caused him to pull dialysis catheters from his arm in the midst of treatment; the interdisciplinary team taught him ways to self-regulate to manage anxiety. William now teaches those skills to other anxious patients:

> They had a new boy who came . . . he had the same problems I had, and I talked to him about how to overcome his panic attacks and stuff. . . . I asked his parents if it was OK to do with him, and they said yeah. So I did help him with that. That helped him out.

As a pathway to hope, learning wisdom is clearly related to the pathways of real/izing connections, claiming power, and attending to God. All four can be nurtured by the team through a particular set of intentional practices.

Pathways to Learning Wisdom

Our research partners say the most important practices for learning wisdom are the honest sharing of medical information, the teaching of health-management skills, and medical actions consistent with the words of team members. Two additional practices seem to contribute to the growth of altruistic wisdom. The first is conversation with team members that helps children name the gifts they have developed as a result of their relationship with end-stage renal disease and discern how they want to respond. The second is the facilitation of mentoring relationships between children at different stages of the disease process. Both practices are primarily spontaneous and informal at the hospital where our research partners are treated; if team members become more intentional and formal about these practices, it could result in more robust hopefulness among children with end-stage renal disease.

Eschatology and Children's Accounts of Hope

Elsewhere, we propose the ancient Semitic tradition of the sojourner as a useful biblical and theological frame for understanding the experiences of children with end-stage renal disease.[26] Children with the disease enter a foreign territory as sojourners—strangers asking for protection and support from local patrons. They dwell in that territory for the rest of their lives, pitching their tents in the midst of a community that offers local wisdom without expecting the children to give up the identities, traditions or resources of their native places. Rather, those gifts and resources become woven into, and benefit, the life of that local community. Hope emerges when and where a child's gifts to the community overlap with and amplify the wisdom of the interdisciplinary team. These communities can become outposts or manifestations of

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[26] Bidwell and Batisky, "Abundance in Finitude," 49-51.

eschatological abundance in the finitude of the present moment,[27] demonstrating the common wealth[28] (or "kin-dom") of God.

Our research partners repeatedly locate hope in the present, experienced during ordinary moments in community, especially unstructured time enjoying family, friends, and team members—what 18-year-old Tom, a transplant recipient, calls "all the good things in life." Some research partners also experience God in the midst of their suffering as a comforting, kinesthetic presence that reassures them about their ultimate well-being. The emphasis that chronically ill children place on the present when talking about hope contrasts significantly with recent theologies that emphasize the future and topocentric dimensions of hopefulness.[29] Certainly, the dominant North American culture is suffused with an apocalyptic, futurist, and topocentric eschatology.

Children's recognition of day-by-day abundance in the midst of the finitude of illness may reflect a lived experience of the actualized or realized eschatology of Charles Dodd, in which the "final things" are a present reality to the people of God.[30] It also resonates with sapiential or wisdom eschatologies evident in John Dominic Crossan and other contemporary theologians, in which the whole of creation is being transformed—through divine and human

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[27] See Rita Nakashima Brock and Rebecca Ann Parker, *Saving Paradise: How Christianity Traded Love of This World for Crucifixion and Empire* (Boston: Beacon Press, 2008).

[28] See Hopkins, *Being Human*, for a fuller description of "God's common wealth." It is a central theme of the text.

[29] See Bidwell, "Eschatology and Childhood Hope."

[30] See Charles Harold Dodd, *The Parables of the Kingdom* (London: Collins, 1969).

action—to manifest here-and-now, in the midst of brokenness, the wisdom, beauty and goodness of God.[31]

And it is God, not Jesus, whom these children focus upon. Although the locus of hope in the Christian traditions is almost always found in the person and work of Jesus Christ, none of our research partners made explicitly Christological claims in relation to hope. For our research partners, eschatology is neither an ultimate, apocalyptic event nor an ultimate, soteriological person or place; rather, it seems similar to, but not exactly like, Dodd's "kingdom version" of realized eschatology in which the common wealth of God is an ongoing, historical and contextual manifestation of God's promises made real through the actions of a called and gathered community.[32] The sojourner participates *now* in the realities of the future promise through a "bond of hospitality" with a community whose practices in a particular context reflect God's role as the special protector of the poor, weak, and disinherited.[33]

Conclusion

Hope manifests among some children with end-stage renal disease through the pathways of vision, voice, faith, community, and identity. It is received and perceived in the present moment through awareness of God's abundance in the midst of chronic illness. Additional

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[31] See John Dominic Crossan, *The Essential Jesus: Original Sayings and Earliest Images* (Edison, NJ: Castle Books, 1994).

[32] See Dodd, *Parables of the Kingdom*.

[33] R. J. D. Knauth, "Alien, Foreign Resident," in *Dictionary of the Old Testament: Pentateuch*, eds. T. Desmond Alexander and David W. Baker (Downers Grove, IL: InterVarsity Press, 2003), 26-33; see also T. M. Mauch, "Sojourner," in *The Interpreter's Dictionary of the Bible*, *Vol. 4*, (Nashville: Abingdon Press, 1962), 397-398.

research should assess how well theological, psychosocial and medical literatures address the elements of hope identified by these particular children living with end-stage renal disease. Their accounts may require a re-interpretation of predominately Christological, future-oriented, and individualistic understandings of hope. Finally, these accounts suggest that hope-nurturing practices can be taught to, and intentionally employed by, members of the interdisciplinary team. When this occurs, the practices must remain relational, contextual, and mutual to preserve the character of the actions that children describe as helpful.

Implications for Pastoral, Clinical, and Community Practice

Hopeful children—those who find meaning in their disease, feel empowered to manage their illness, successfully integrate chronicity into previous identities, develop a sense of altruism as a result of their illness, and anticipate future achievements—are more likely to take their medications; follow medical instructions to avoid rejecting a transplanted kidney; and manage their illness to maintain good kidney function, increase independence, avoid hospitalization, and qualify for less-demanding dialysis schedules.[34] Without question, the health and economic benefits of nurturing hope among children with chronic illness deserve the attention of spiritual caregivers, religious leaders, and members of the interdisciplinary treatment team.

Beyond material benefit, however, there are also significant spiritual, existential, relational, and communal reasons to become more intentional about nurturing hope among

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[34] Julie M. Maikranz, Ric G. Steele, Meredith L. Dreyer, Aaron C. Stratman, and James A Bovaird, "The Relationship of Hope and Illness-related Uncertainty to Emotional Adjustment and Adherence among Pediatric Renal and Liver Transplant Recipients," *Journal of Pediatric Psychology* 32/5 (2007): 571-581.

chronically ill children and adults. Our research has at least three primary implications for this goal in relation to pastoral, clinical, and community practice.

First, our work makes clear that children with end-stage renal disease are aware of what's going on with their bodies, their psychosocial circumstances, and their medical care; they also reflect with insight on their experiences of illness. Chronically ill children make meaning of their suffering in creative and nuanced ways. Having clear, honest and accurate information from members of the interdisciplinary team facilitates this process, and children with end-stage renal disease trust and value adults who know that children are, as pastoral theologian Bonnie Miller-McLemore argues,[35] responsible, knowing agents who have ever-emerging and -maturing spiritual, moral, communal and health-related powers. Again and again, children demonstrate that they know more about their health and illness than team members tend to assume, and children say that accurate, honest medical information provides them with another, especially effective tool, for cope with their illness. This suggests that caregivers of all types should provide specific, detailed and developmentally appropriate information to children living with chronic illness, paying as much or more attention to their needs for information than to adults with the same disease.

Second, this research suggests that spiritual caregivers, medical team members, clinicians, and faith communities could do more to cultivate noetic awareness in children with chronic illness, opening them "to knowledge that comes . . . directly through . . . subjective

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[35] Bonnie J. Miller-McLemore, *Let the Children Come: Reimagining Childhood from a Christian Perspective* (San Francisco: Jossey-Bass, 2003).

experiences or inner authority”[36] rather than through discursive thought. Such knowledge can be cultivated and accessed through intuition, imagination, creative processes, spiritual insights and practices, and other epistemological events. This type of direct and spiritual knowing contributes significantly to the pathway of “learning wisdom,” as well as to other pathways in our preliminary model; it also seems operative in children’s eschatological descriptions of moments when hope is most present to them.[37] Children who say the disease has clarified their vocation, bestowed special gifts or knowledge, and created altruistic motivation often attribute their insights to a noetic awareness that carries significant authority for them. Practices of curiosity, prayer, mindfulness, creativity, and introspection (in both the psychological and spiritual uses of the term), among others, can help cultivate noetic awareness.[38]

Finally, our work clarifies that hope is nurtured in many, idiosyncratic ways; singular or mono-dimensional understandings of hopefulness cannot be effective for all people. Because no child or family hopes in the same manner, it is essential that pastoral, spiritual, clinical, and community caregivers identify the specific pathways to hope already present to each patient and family and intervene to access and strengthen those pathways in relation to the experience of chronic illness.

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[36] Marilyn M. Schlitz, Cassandra Vieten, and Tina Amorok, *Living Deeply: The Art and Science of Transformation in Everyday Life* (Oakland, CA: Noetic Books and New Harbinger Publications, Inc., 2007), p. 4.

[37] See Bidwell, “Eschatology and Childhood Hope.”

[38] Schlitz, et. al., *Living Deeply*, 66-114.