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Issue Topic: Adolescents and Young Adults

Welcome to the 81st issue of our Pediatric e-Journal. The focus of this issue is topics that involve adolescents and young adults. We recognize that even a full issue will not be sufficient to provide exhaustive coverage of these matters, but we hope that the articles offered here will spark broad discussion of this important subject area.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Alliance for Care at Home (the Alliance). The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Melissa Hunt. Chuck Corr is our Senior Editor. Archived issues of this publication are available at allianceforcareathome.org/pediatric-e-journal

Comments about the activities of the Pediatric e-Journal Workgroup or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are open to suggestions for the issues that will follow in 2026. Our tentative plans are for Issues #82 and #83 to address trauma and trauma-informed care, with the first to focus on patients and families, and the second to focus on providers and care teams. Then we are planning to focus Issue #84 on spiritual support. If you have any thoughts about these topics or other subjects and/or potential contributors (including yourself?) for future issues, please contact Christy Torkildson at Christy.Torkildson@gcu.edu or Melissa Hunt at melissa.hunt@handsofhopese.com

Views expressed in this and other issues of the Pediatric e-Journal are exclusively those of the authors and do not necessarily reflect the views of the Pediatric e-Journal Workgroup, the Pediatric Council, or the National Alliance for Care at Home.

Produced by the Pediatric e-Journal Workgroup

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The author of this article was two years old when her sister, Soraya, was born. Soraya soon developed medical complications that have affected her entire life. The point here is that they also affected Yasmeen’s life: “Not that it was my parent’s fault, but for most of childhood, I grew up in the background. Soraya came first.” Yasmeen is now 16. Her article describes challenges the entire family has faced, special problems she faced, and where she got help, with special attention to the needs of the sibling of a child with such complications.

The authors of this article explore transitions that “are of particular concern for AMC [adolescents with medical complexity] with progressive, degenerative conditions and their families,” as well as of their professional care providers. In this article, they explore some of the many variables that can influence these transitions. They propose a “call to action [that] argues for attention to social determinants and family health screening, including individual parent and sibling psychosocial health” and insist that “To meet the needs of the growing population of AMC and young people with serious illness, the current conceptualization of pediatric-to-adult health transition has to move beyond provider-patient only to a family-centered approach.”

This article begins from the following: “As the medical world continues to change and adapt to best practices, there has been a shift to acknowledge the importance of providing a voice to children of all ages in their medical care.” If that is so, then “developmentally, how can parents, medical decision-makers, and providers support a child’s voice and provide opportunities for assent?” Key points include: recognition of a child’s wishes; developmentally-appropriate ways of responding to those wishes; and adapting the practices of caregiving teams to promote each child’s autonomy.

Considerations for Using Five Wishes with Young Adults and Teenagers p. 14

Danielle Eaves Hernandez, MPH, CCLS, CTRS, GC-C, CPH

The Five Wishes document is a legally valid way of expressing and honoring an individual's wishes for end-of-life care. Voicing My Choices is a similar document designed for teenagers and young adults. This article recommends using the last two wishes in these documents that focus on how individuals want people to treat them and how they want people to remember them. In that context, these wishes can be the basis for an ongoing, evolving dialogue between youth patients and family members and members of the professional care team. Three examples of terminally-ill teenagers illustrate how options "should include giving teenagers and young adults options to have living funerals or plan their own, to celebrate holidays early, to create bucket lists, to take a wish trip, and other customized ways to say goodbye to their loved ones on their own terms. This also includes designating how memorial funds are routed to their families and/or foundations to find a cure or give back to a cause that supported them."

When Can Adolescents Make Their Own Health Care Decisions? p. 17

Robert C. Macauley, MD, FAAP, FAAHPM

This article offers a sophisticated and detailed analysis of the question posed in its title. Account is taken of relevant Supreme Court decisions, state laws, medical practice, the context of palliative care, and pertinent literature

Family Centered Pediatric Advance Care Planning for Teens Living with HIV and Cancer (FACE-HIV; FACE-TC) p. 22

Maureen E. Lyon, PhD, FABPP, FSAHM

This article summarizes work to develop FACE-TC, which is "the only pediatric advance care planning program recognized by the Evidence-Based Cancer Control Programs by the National Cancer Institute." The program consists of "three approximately 45 minute sessions administered weekly and facilitated by a trained/certified facilitator": "Session 1. The Lyon Advance Care Planning Survey is administered separately to the adolescent and chosen surrogate decision maker(s) if the adolescent is age 18 years or older or to the adolescent's legal guardian(s)"; "Session 2. The Respecting Choices Next Steps conversation guide"; and "Sesson 3. The Five Wishes." The balance of this article offers an explanation of the advantages of this program and illustrates how it can be implemented.

In this article, the author addresses the question of "what becomes of those children who reach the age of 21 and must then choose to either continue curative care and forfeit their hospice care benefits or vice versa." A case example of a 20-year-old patient illustrates these issues and notes that, "Much to the appreciation of both the patient, his family, and our hospice team members, the petitioned insurance group agreed to continue his inpatient payments." In conclusion, the author observes that, "A future in which all individuals regardless of their age have the right to concurrent care seems appropriate. However, this seems unlikely at this time for several reasons including financial restraints…One might think that seeking continual concurrent care for a newly turned 21-year-old fits the definition of appropriate use of resources and is simply the just thing to do."

This article addresses events that occur throughout life and subsequent losses that may occur. In light of such events and losses, the author argues that "it is essential for the Pediatric Palliative Care team to communicate with the patient and family to address concerns related to these ongoing losses and the experiences they create for this child and family. These ongoing losses may impact goals of care. They may lead to reflection and re-goaling to meet the changings needs and perspective on quality of life for this patient and family." The author notes that anticipatory grief and bereavement may occur in connection with all such events and losses. She then places such anticipatory grief and bereavement in a developmental context and offers suggestions of books and other grief resources for children and teens.

The concluding piece in this issue is a summary and review of a recent article from the journal, Pediatrics, entitled "The state of pediatric concurrent hospice care in the United States." The review explains the current state of this particular form of care (with its challenges, barriers, and successes) and identifies where we might go from here.

The Questions We Should Ask

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I have a way with words. I'm great at public speaking, holding conversations, etc. Yet there is one question that will forever stop me in my tracks. The question being, "How's your sister?" I freeze, panicking for an answer. How much should I share? Should I tell the full truth or keep things light? How much do they already know? How much energy do I have to be able to share? Questions like this circle my head, but my answer usually defaults to "She's alright." At one point in my life, maybe in elementary or early middle school, this would've been the truth most days. Now, it's mostly a lie. A lie I tell to keep the heaviness that is my life out of conversations, and a lie I tell to keep myself afloat. This is just one example of how I do that, keeping myself afloat. Having a sister with an undiagnosed disease that is slowly killing her forces me to adapt, to keep afloat no matter how much that reality wishes to sink me.

My younger sister, Soraya, was born when I was 2 years old. I don't remember much of my life at that age, but I remember the shift in my house from the moment my sister was born. Something wasn't right. One of my earliest memories is when my parents videoed Soraya's reflux and gurgling when fed solid food, the way that her breathing showed there was fluid going into her lungs, and I remember how I was told to be as quiet as possible. She was proclaimed undiagnosed, and then started my parents journey to give their new disabled child the fullest life possible. Given she was developmentally delayed, had a G-tube for food and water, and needed multiple types of therapies, that wasn't easy. One factor I wish my parents had taken into account while keeping Soraya alive, rather selfishly, is me.

Not that it was my parent's fault, but for most of childhood, I grew up in the background. Soraya came first. At doctors' appointments I would just sit as an accessory, and at my sister's many therapies, I would sit in a dark room alone. I vividly remember having to sit for hours in a small, unlit room with just a few toys and my iPad, occasionally, from ages 2-5, just playing by myself. I was physically healthy, so why worry about my needs? Even though set aside, I of course still felt my parent's love. I just knew I was not going to be the priority. By the time my second sister, Leena, was born, Soraya had somewhat stabilized. We then moved from Virginia to Cincinnati, Ohio, for health care at Cincinnati Children's. While I firmly believe a lot should be changed in the healthcare system, I owe Cincinnati Children's so much for all they've done for my family.

For the next 7 or so years, I lived what I like to call the "typical" special-needs-sibling life. I lived in my sister's medical shadow, grew resentful of the normal life I'd lost, and had to deal with carrying all of the experiences so unique to being a sibling of someone with a disability seemingly alone. That in itself was hard, considering it felt like I was carrying the weight of worlds on my shoulders before I was even in 1st grade. So, thank goodness I found Siblings With A Mission, a non-profit based in

Cincinnati that was made to connect siblings like myself to other siblings. I started working with them when I was 7, and am now on their leadership team 9 years later. Having a sibling space like that has helped me so much, especially when things with Soraya became terminal.

Going into the end of my 7th grade year, my family went to Hawaii for my sister's Make-A-Wish. I would be going to an all-expenses-paid trip to Hawaii with my closest family and friends for a week, but because my sister was going to die. While some of my greatest memories are from that trip, there was a cloud that started to hang over me when our Make-A-Wish experience started, and things started changing rapidly after that trip. My sister was put into a child hospice program called Starshine, where specialists from Cincinnati Children's come to my house and do activities with my sisters and I once a month or so. It was also at that point my parents started to realize how much ALL of their kids needed more support. Once things took a graver turn, they started to give each of us more grace, more understanding, and more individual care; especially for Leena and I. We as a family have started to "Suck the Joy Out Of Life," as our catchphrase calls it; chasing after the joy that is clouded by the darkness that became our life.

Soraya has lost so much over the past few years. We now have wheelchairs and stairlifts on every floor, she is on a BiPAP for 15+ hours a day, she rarely moves off the couch due to muscle weakness, and is on heavy opioids for all of her pain. I am unsure of her timeline, but her decline has taken her so far away from that girl learning to surf in Hawaii. Her disease is close to fully consuming her, and I continue to battle my own demons.

Looking back on all these events now, I am realizing that while I have been torn up by some of these experiences, I have been lucky enough to have support to sew myself back together. However, not just any support. SIBLING support. From organizations: Siblings With a Mission has always made me feel less alone even when at times it felt like I didn't matter. They gave me a voice to advocate for both siblings like myself and for people like Soraya. From hospitals: Cincinnati Children's is opening up a new Sibling Center for siblings like myself, a center I've helped create/advocate for, so no kid has to sit in a dark room like I did while they wait for their siblings to get care. From my parents: the effort to take care of both my AND Leena's needs and wants like they do Soraya's, within reason considering her circumstances.

Another important aspect is the impact of being heard. I felt like a burden simply for feeling and being for so long; feeling like the fact my parents had to deal with my needs on top of my sisters was unfair to them. It was when Soraya got into hospice and my parents started focusing consistently on what all three of their daughters needed that that weight started to lift. It still weighs on me, but it is a lot lighter now that I have been shown that my feelings are worth being shared. That I am not just Soraya's sister, but that I am Yasmeen, who is sister's with Soraya.

I am no longer living in my sister's medical shadow. I have been able to embrace that I am my own person, with my own strengths and weaknesses, my own personal story. Sure, my sister is a part of that, but I am still my own person. While that may sound obvious, from what I have seen most siblings like me feel that they are simply an extension of their medically challenged sibling, which is the furthest thing from true. We are just as important to the family unit as anyone else, the glue of the family, even I like to say. The fact it took me such a long time to realize that I am allowed to be my own person is something I wish I could have had the resources to figure out earlier. That is why it is so important to make sure siblings like myself are supported. Things like parents actively working with their non-terminal child to make sure their wants and needs are met, treating them with the same concern and validity as their terminal child, are things that have made a huge difference in my own experience and the experience of others. Or, things like doctors and specialists keeping siblings in the loop to make sure they don't feel cast aside, and if the sibling doesn't want to, making sure they have a space to be that doesn't make them feel like an added weight. And finally, the most important aspect. Making sure us siblings are heard. There is nothing worse than struggling while asking for help on deaf ears. The misconception that the person struggling the most in a terminally-ill child's family is the child that has to end. The anticipatory grief for the rest of the family, and for the siblings, is just as heavy. Talk to us, ask us questions, treat us like we are just as important in the struggle as our sibling.

Speaking of, remember that first question I mentioned? Another thing doctors, parents, family, friends, etc. can do to help us siblings is ask instead of “How is your sister?” is “How are YOU?” Our sibling isn't the only one struggling, we are too, but acknowledging that we are all on the struggle bus is the first step in smoothing out this ride.

Rethinking the Shift from Pediatric to Adult Health Care in Serious Illness

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Healthcare transition is a global concern for adolescents with medical complexity (AMC) living with chronic and life-threatening conditions.[1] Many AMC and their families will potentially face the challenges and uncertainty associated with pediatric to adult transition.[2] These transitions are of particular concern for AMC with progressive, degenerative conditions and their families, but have received less attention. Families who may not have expected their child to survive into young adulthood must now consider the opportunities and risks of transition, such as ending relationships with pediatric clinicians and specialists, who often employ a family-centered approach, and transitioning to adult health specialists, who often apply a person-centered approach. Considering families continue to provide most illness-directed care and management to these AMC, this transition is complex.

The needs of AMC are intense and may become more so with age. For example, as AMC age and mature, their disease may progress, and they may lose functional milestones. This means their family caregivers, most often parents or siblings, must render more intense care even as their own ability to do this diminishes. What had once included lifting a small child that could be accomplished by one parent may require two aging parents to lift their adult-sized child. With age, AMC also lose access to certain youth and family-centered services, such as in-home nursing care and therapeutic supports. These young people do not just need **any** support—they need the developmentally **right** support that meets each AYA where they are developmentally and allows for maximal agency that is aligned with their preferences. Thus, in order to maintain high-quality outcomes for AMC and maintain family caregiver health throughout the transition age period, our models of transition care may need to adapt to address these challenges.

AMC and their families in the U.S. may be simultaneously affected by social determinants of health, such as historical barriers to accessing care, hurdles associated with delivery of palliative and hospice care (e.g., geography), disability level of AMC, family income and resources, and AMC and parent mental health.[3] In addition, AMC and parents continue to experience physical and developmental changes over time that can increase their risk of negative physical and mental health effects. For example, as all family members age, they may experience diminished health status or lose function. Developmental milestones may be at risk, too, as the AMC may not be able to achieve independence and the parent may not be able to have a pause in caregiving responsibilities.

Our research team wanted to understand the impact that policy and contextual factors could have on the pediatric-to-adult health transition for AMC and their families. First, our team was struck by the disruption in services that AMC who require the supports of concurrent hospice care and their families face as the young person approaches 21 years of age. Those nearing 21 years must decide whether to shift to adult hospice or leave hospice for life-prolonging care. This decision may be particularly challenging for young adults with cancer, given the intensity of oncological care. Yet, little is known about the needs of these potentially vulnerable youth. Thus, we compared young adults with and without cancer in concurrent hospice care. We conducted a retrospective comparative study using data from the 2011-2013 U.S. Medicaid data file.[4] Young people who died were included if they were 20 years of age, enrolled in Medicaid hospice care, and used non-hospice medical services on the same day as hospice care based on their Medicaid claims activity dates.

Among the 226 20-year-olds who died, 21% had cancer. More than half were female (60.6%), Caucasian (53.5%), non-Hispanic (77.4%), resided in an urban area (58%), and had mental/behavioral health disorder (53%). Young adults with cancer were more often African American/Black (68.7% vs. 40.4%), technology dependent (47.9% vs. 24.2%), and had comorbidities (83.3% vs. 30.3%). Those with cancer were more likely to live in rural (58.3% vs. 37.6%), southern (41.7% vs. 20.8%) areas compared to peers without cancer. Youth with cancer had significantly fewer live discharges from hospice (5.7 %vs. 17.3%) and sought treatment for symptoms more often from non-hospice providers (35.4% vs. 14.0%). We learned that youth in concurrent hospice care live with medical complexity, even at end of life, and clinical and demographic differences among young adults with and without cancer in concurrent care highlight needs for research exploring barriers to accessible care at key transition points.[4]

To understand these barriers to accessible care at key transition points, our team sought to describe the relationship between social determinants of health and high-quality pediatric to adult health transition care for AMC 12-17 years of age. We recognized that AMC are living longer lives and may be expected to transition to adult health care and that current systems and policies of transition care may not reflect their needs, family needs, or the impact of social determinants of health.[5] To do this, we conducted a retrospective cohort study of the 2019-2021 National Survey of Children's Health, informed by the Healthy People 2030 description of social determinants of health.[6-11]

The AMC and parents in this sample experienced important sources of risk, including financial and food insecurity. Twenty-five percent of parents reported experiencing inadequate emotional support and nearly half of the AMC experienced two or more adverse childhood events. Looking specifically at the relationship between social determinants and high-quality health transition, several key findings stand out. Parent college education and level of aggravation were negatively associated with professionals' active management of an AMC's pediatric to adult transition. Lower socioeconomic status among youth was negatively associated with their physician actively managing their transition to adult healthcare, demonstrating how poverty can negatively impact successful pediatric-to-adult health transition. Finally, family-level factors, such as parent experience of emotional support and level of aggravation, are negatively related to high-quality transition practices and outcomes.[11]

The findings of this study supported what we learned through conversations with families caring for AMC: they face the cumulative impact of multiple, competing demands. Social determinants of health, such as economic status, community support, and access to healthcare, have a significant impact and should be considered in transition care. For example, poverty can negatively impact successful pediatric-to-adult health transition. Given that youth constitute the poorest segment of the U.S. population, our results add to the evidence about the ways that poverty impacts child health by articulating the particular experience of AMC and their families. Youth living in poverty experience worse health outcomes; for AMC moving through different health care settings, this impact may be compounded.[12]

Family level factors are related to high-quality transition practices and outcomes, supporting the idea that family is both a determinant of health and affected by social determinants.[13] This may seem common sense to many professionals devoted to child health, yet current models of care may not consistently assess and address parent or family health or screen for impact of social determinants. We hope the findings of our study will prompt pediatric professionals to incorporate screening for social determinants and parental/family health into practice with AMC. Just as financial and food security are important resources for AMC, parent and family health are powerfully important resources and warrant attention.[13, 14]

The most important and impactful source of information about pediatric-to-adult health transition among AMC were the stories of families. Through a series of blog posts, essays, and interviews, parents shared their daily lived experiences of joy and challenge in caring for their adolescent or young adult with medical complexity during this transition. They described how loss of services affected an already tenuous balance and the ensuing fights they undertook to care for their child at home in a way that aligned with what was important to the young person and family. They discussed the overwhelming mental gymnastics a parent or other family caregiver must undertake to address the legal requirements of pediatric-to-adult health transition, in addition to the required changes in healthcare settings and providers. For many parents, this transition process amounts to a full-time job on top of their daily caregiving role.

As AMC age into the adult health landscape, families and youth alike experience wave after wave of transition. The resources families have to manage this transition and loss of services are affected by social determinants, such as health care accessibility/quality, socioeconomic status, and geography. The loss of services is challenging, gradual, and exerts a cumulative impact. In this series of quotes, one mother depicts the continuing waves of challenges that the policies guiding care of young people with medical complexity exerted on her family:

- **As young person turns 18 years of age:** “We fought for legal guardianship and government benefits, for resources to modify our home, as he grew larger in size and as his health declined, for home based medical care as he lost skills and medical stability.”
- **As young person turns 19 years of age:** “He turned 19 and aged out of pediatric palliative care. We fought again. Fought against regulation and red tape and to reinstate the lifeline of palliative care that we had grown to rely on. That helped us help him. That gave him measures of comfort. That gave us the resources we needed to keep him home and out of the hospital and safe and stable.”
- **As young person turns 21 years of age:** “Now, he is 21. He could no longer receive hospice services simultaneously with home nursing supports.”

Swoyer, B., 2019[15]

Considering what we have learned from families across data sources, we propose a call to action. This call to action argues for attention to social determinants and family health screening, including individual parent and sibling psychosocial health. Current research reveals that gender, race, and socioeconomic status significantly affect transition outcomes. Yet, structural drivers of health—like racism, ableism, and systemic discrimination—are rarely studied. Marginalized youth are less likely to receive transition planning, more likely to experience gaps in care, and often face mistrust or stigma in adult systems. Transition programs must be culturally responsive and inclusive.[16] Family health is both a determinant of health and affected by social determinants of health. Families are a vital and non-renewable resource in the care of young people with medical complexity.

To meet the needs of the growing population of AMC and young people with serious illness, the current conceptualization of pediatric-to-adult health transition has to move beyond provider-patient only to a family-centered approach. Parents and caregivers are often deeply involved in care coordination, advocacy, and emotional support. Yet, they face evolving roles and disrupted services during transition that can be disorienting and distressing. Families report feeling unprepared, excluded, or unsupported in adult care settings. Professionals can guide parents through this shift, validating their expertise while helping them foster the young person’s role in their healthcare.[16-18] Such a move recognizes that each family member and the family system are affected by this change in care and services while experiencing their own transition, too.

We argue for integration of services that bring siloes of health, law, education, and insurance together, perhaps through patient navigators or care coordination. Transition is not a single event but a multi-phase process that must be personalized, developmentally appropriate, and relationally grounded. Models from which we can learn exist in the aging-in-place and aging-at-home-space where an interdisciplinary team of nurse, OT, and carpentry visit older adults who want to age at home to help make accommodations possible. Working with AMC and parents as partners to co-create transition policies and programs and using their feedback to improve services and ensure relevance will be a crucial step.

Such changes will always require negotiation with and adaptation of policy at agency/institutional, county, state, and federal level, illustrating how policy is a major determinant of health. To capture this piece, we need evidence from a broad base of constituents, such as parents, siblings, family caregivers, youth, clinicians, administrators, policy makers using a community engaged approach to learn what is needed, what is meaningful and acceptable, and what is possible.

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Providing Developmentally Appropriate Opportunities for Assent

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"I don't want to go back to the hospital."

It's a common phrase in the pediatric medical world—regardless of age, diagnosis, or treatment protocol. It's a phrase that many adults feel as well but may instead keep to themselves. At some point in development, it is as if the voice of assent was stifled. As the medical world continues to change and adapt to best practices, there has been a shift to acknowledge the importance of providing a voice to children of all ages in their medical care. However, this has also included the growing difficulty at navigating the ethics of assent and legal consent for children in healthcare decision making. Developmentally, how can parents, medical decision-makers, and providers support a child's voice and provide opportunities for assent?

It is imperative to recognize that chronological age does not equal developmental age, therefore an individual approach should be taken with every child to assess their developmental threshold for understanding and functioning. The child's understanding of the world around them is what informs their decision-making and perception. Especially in situations of prolonged stress, trauma, and illness, development may be stunted while chronological age continues. By that same token, many children may also have an adult-like perception of the world based on their exposure to procedures, decision-making, and conversations. It is important to note that development may ebb and flow, plateau and regress. Special care should be taken in assessing and understanding a child's developmental understanding and capacity when working with them in navigating care. Milestones may be adjusted based on a child's experiences and, therefore, encourage the healthcare system to take a humanistic and individualized approach.

Expression is also informed by the child's development. An infant may cry and show signs of distress when facing fearful situations. A young child may use play to indicate their understanding, while someone in adolescence may focus more on the perceptions of their peers (Levetown, 2008). Regardless, the importance of recognizing, responding, and adapting are essential in navigating decision making. Assent, the emotional agreement of the minor child, can be given or revoked regardless of the legal consent that may be provided by the decision-maker. It is the child's assent that helps guide opportunities for autonomy and can be a tool to honor a child's wish collectively.

Recognition

The recognition of a child's wishes, especially as it relates to trauma, requires understanding of the developmental stage as well as patience in the process of communication. In breaking down the common phrase "I don't want to go to the hospital," we can see that there may be various subtexts that should be recognized and then explored.

"I don't want to go to the hospital"

"I don't want to have any more needles"

"I don't want to continue treatments"

"I want to feel normal"

Taking time to explore the individual's true reasoning behind the statement will allow for more opportunities to respond and adapt to their wishes. This may offer the opportunity to uncover potential trauma triggers to inform ongoing practice and approach. In early childhood, there may be limited language to fully express their feelings and desires (Vygotsky, 1962). As youngsters progress in age, that limited language and emotional intelligence begins to morph into a decisional language. Meaning, there becomes a choice of what and how much to share that is often reliant on trust and rapport. Despite not knowing what the subtext may be, there is potential to begin the responsorial process once there is the recognition that there may be more to the initial expression.

Response

Appropriate and developmentally-informed strategies for responding to a child's expression are crucial in building rapport, obtaining more information, and working towards strategies to promote assent and autonomy. The response should be rooted in developmentally-appropriate interventions with the goal of gaining more information about the statement or desire while simultaneously offering reassurance and support (Sisk et al, 2016). As each developmental stage progresses, this allows skills to build into more complex and abstract approaches while maintaining access to a more simplified approach if needed. There is also an inherent growth of indirect engagement to more directed interactions as skills grow including language, emotional intelligence, and social awareness. For example, provider responses may be more tailored to promote a calm and supportive presence in infancy rather than eliciting or processing information as it would in adolescence.

Infancy (0-2)	Early Childhood (3-6)	Childhood (6-12)	Adolescence (12-18)
Caregiver Proximity	Imaginative Play	Play Personification	Verbal Discourse
Reassurance Strategies	Art/Music Exploration	Art/Music Creation	Art/Music Interpretation
Sound and Singing	Verbal Reassurance	Verbal Reasoning	Processing and Coping

By tailoring responses to the developmental stage of the child, there is an increased potential for positive response that can then inform how to adapt the practice. Oftentimes, the information gathered during this stage will lead to a better understanding of what the child wants and their assent for ongoing care and limit traumatic experiences.

Adaptation

As a provider can grow into their understanding of the child's desires and perspective, there becomes an ability to then adapt their practice to promote autonomy. Through decades of research, there is evidence to indicate that children who are offered the chance to participate and help guide their care have positive mental-health related outcomes and less reports of medical trauma (Barlow & Ellard, 2006). Although a child under 18 may not have legal consent for their care, their assent is essential to their coping, participation, and emotional well-being. Upon gaining more insight into the "why" behind the statement, more information can be offered, and approaches can be tailored to help promote coping, dismantle any incorrect narratives, and potentially open the door for other strategies. Adaption will often include opportunities for choice where appropriate. For example, we may have to provide treatment but there can be opportunities for choices within that treatment such as a preferred side, placement/positioning, or colors of bandages (Thompson & Stanford, 1981). The integration of therapeutic play and creative arts interventions can provide additional opportunities for choice and validation that can offer a sense of control and autonomy. Adapting the intervention an approach to the individual can promote a better sense of self with the hope of decreasing feelings of anxiety, fear, and distress during traumatic events (Ferro & Boyle, 2015).

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Considerations for Using Five Wishes with Young Adults and Teenagers

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Five Wishes is a legally valid document that honors an individual's wishes for end-of-life care. Five Wishes was developed in 1996 by attorney Jim Towey with the organization he founded, Aging for Dignity. He created this document after serving as legal counsel to Mother Teresa and witnessing her powerful work with the Home For the Dying in the United States. This simple booklet grants individuals the power to define who they want to make healthcare decisions when they are unable to, the kind of medical treatment they want or do not, and how comfortable they want to be. Wishes four and five focus on how they want people to treat them and how they want people to remember them. A young adult version, *Voicing My Choices*, was developed, along with a corresponding version for younger children titled *My Choices*. (Aging with Dignity, n.d.)

While patients, caregivers, and professionals all wish we can change a terminal prognosis, we can grant control to our patients by giving them the ability to die on their own terms. "Allowing adolescents to be more involved in their health care decision-making processes, especially at end-of-life, can help reestablish their burgeoning autonomy and sense of purpose" (Wiener et al., 2012). While parents often serve as the primary gatekeepers to their child's care, adolescents and young adults uniquely confront the decline of their own bodies and the reality of imminent death. "Decision making itself is important for the adolescent and has been linked to better coping and adjustment" (Klopfenstein et al., 2001). There are many decisions for end-of-life which include patients sharing their death location preference, how they can be remembered at school, and having their treatment plans honored.

While end-of-life conversations often begin with a single, difficult—and sometimes dreaded—discussion, these should continue as an ongoing, evolving dialogue with each interaction of the interdisciplinary team. The patient and family need to feel consistent validation that this is difficult situation and they are not alone throughout the end-of-life process. When words are difficult to find during these difficult conversations, Five Wishes acts as a guide in which patients can complete the whole booklet in one sitting or in sections at different times at their discretion. Not only does this aid the care team and patients, it also serves as a template for an otherwise daunting and unimaginable conversation for parents. A study found that none of the parents interviewed who lost a child to cancer regretted that they had discussed the child's death beforehand, while 27% of those who did not discuss end-of-life did regret that they had not done so (Kreicbergs et al., 2004).

When it is not ‘it is not possible to save a life, it is as important and can be as rewarding to ‘save a death’ (Baverstock & Finlay, 2008). Options for a “good death” should include giving teenagers and young adults options to have living funerals or plan their own, to celebrate holidays early, to create bucket lists, to take a wish trip, and other customized ways to say goodbye to their loved ones on their own terms. This also includes designating how memorial funds are routed to their families and/or foundations to find a cure or give back to a cause that supported them. Additionally, some young adults decide to donate their tumors or body to science or to donate tissues or organs to others if possible.

“Creating a good death experience that frames the end-of-life time period in a way that builds memories, legacy and honors families’ ongoing love and connection, is both possible, doable and rewarding” (Broden, Deatrick, Ulrich, & Curley, 2020). Patients, families, their community providers, and wish-granting organizations have the opportunity and often a limited time frame to work together to identify what dignifies a “good death” for each patient. “Legacy building and memory-making are two different concepts, though often intertwined. Legacy building is a “process of leaving something behind…one’s belonging, one’s memories, one’s values, and even one’s body” (Hunter & Rowles, 2005, p. 328).

Memory-making activities transform nervous energy and shift into a positive memory-making experiences full of laughter and tears which are just as powerful as the keepsakes themselves. Child life specialists often facilitate these memory-making projects, but anyone can implement them. Inspiration can be found on the internet through several social media platforms, on Amazon, or walking through a craft store. Keepsakes such as artwork, heartbeat teddy bears, voice recordings, leaving voicemails, or creating videos for the future serve as outlets for creativity and control. Handwritten cards for missed life events prove that their connection is eternal. Another intervention is the use of narrative medicine, in which patients are encouraged to document their medical experiences from their own perspective, thus allowing for control as the storyteller. Hand casting mold kits, handprint canvases, and handwriting jewelry or lockets are additional items that can be done with the family, reframing the experience into one that memorializes the love they share will live on.

Other considerations for memory making include encouraging patients to leave passwords for emails, phone codes, and designating an Apple iCloud legacy contact to access precious photos and memories after they have died. A shared Google drive, thumb drives, printed photo books and ornaments are also treasures that they can give their loved ones. Song playlists provide another meaningful intervention, allowing patients to share their favorite music as a lasting gift to families, offering comfort and connection in the years ahead.

Perhaps the most powerful wish of the five is “How I want to be remembered.” Considerations include bequeathing favorite toys and memorabilia, responsibility for pets, and teaching younger sibling things that they wish they could. This child life specialist has been humbled to learn from each young adult and family she has had the honor of working with. Jaheim, a 13-year-old patient dying of Glioblastoma wrote in his *Five Wishes* to “tell my baby brother that I am a good person and I love my family.” He also created a thumbprint heart card for his sister’s preschool graduation and a Mother’s Day card for his mom. Three years after his death, his mother shared that she frequently reads the *Five Wishes* booklet he completed with the child life specialist and finds peace knowing that she honored all his wishes.

Young adult patients deserve the opportunity to say goodbye to their loved ones on their own terms—with autonomy, dignity, and support. Dakota was a 17-year-old young man who loved Legos and had thousands of pieces. He requested that his mother make resin initials of his name with the Legos embedded in them along with teddy bears he selected to bequeath to his family and hospice team. Another patient named Levi chose to celebrate Christmas early as a "Grinchmas" theme and all present thanked him for the gift he had been in their lives. After an honest conversation about the end of her life, a young woman named Alexis coined the phrase "YODO"—*You Only Die Once*. With that spirit, she set out to make every moment count. She swam with dolphins, celebrated the holidays early, played games with her family, and traveled to New York. Alexis reminded us all that even in the face of loss, life can still be full of meaning. May we all live like Alexis—fully, fiercely, and full of love.

Caption: Grinchmas 2024 with Levi and his hospice interdisciplinary team

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When Can Adolescents Make Their Own Health Care Decisions?

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“Most children,” asserts the prevailing U.S. Supreme Court opinion, “even in adolescence, simply are not able to make sound judgments concerning many decisions, including their need for medical care or treatment. Parents can and must make these decisions” (Parham v. J.R., 1979). Nothing magical happens, though, on your eighteenth birthday. It’s not like you suddenly bequeathed the core components of decision-making capacity (which include assimilation and rational manipulation of information, as well as application of one’s personal values (Grisso & Appelbaum, 2023). As some famous examples prove (Reichard, 2025), there’s no guarantee that (the age of) majority equals maturity. Yet in 46 states (as well as the District of Columbia), an 18-year-old is considered an adult, and thus authorized to make their own medical decisions.

Just as someone over the age of 18 might lack decisional capacity, a younger minor might possess a maturity beyond their years, especially if they have been dealing with serious illness (Stepanek, 2006). Such a teenager might reasonably seek a greater voice in medical decisions that fundamentally impact their life (Weaver et al., 2015). This is especially true for adolescents with cancer (Coyne et al., 2014), with most older teens seeking a precise understanding of prognosis (Mack et al., 2006) and many wanting total control in decision making (Zwaanswijk et al., 2007). Given the stakes involved, some have argued that if cancer is incurable or progressive, the adolescent patient should take the lead because they are the best judge of relative burdens and benefits (Whitney et al., 2006).

Which raises the question of when a patient under the age of 18 should be allowed to make their own medical decisions. The law sets out two clear exceptions. One involves the “minor treatment statutes,” whereby a minor is legally authorized to consent to treatment for specified conditions. (These vary by state, but often include pregnancy, drug addiction, and alcohol addiction, and thus are not often relevant to pediatric palliative care.) The other is emancipation, whereby a minor either meets specified criteria—again varying by state, but often including marriage or active military service—or is declared emancipated by a judge after providing proof of specific measures of independence, such as being financially self-sufficient. Emancipated minors have the authority to make all medical decisions (Coleman & Rosoff, 2013).

Children receiving palliative care don't usually fit either of these criteria, yet some appear able to make thoughtful, rational decisions. Recognizing this, approximately one-third of states have enacted so-called "mature minor" laws, empowering certain patients—such as those who've graduated from high school or proven one's maturity to a judge—to make their own medical decisions (Coleman & Rosoff, 2013). (Clinicians should be familiar with the laws of their own state.) Although initially conceived as a way for minors to receive obviously beneficial procedures (such as a throat swab for strep) when a parent was not available, the "mature minor exception" could also be relevant to situations where an adolescent seeks an intervention their parent is opposed to, or refuses one that their parents favor.

The rationale behind the mature minor exception was supported by clinical studies which called into question the prevailing opinion of the U.S. Supreme Court. Some showed that 14-17 year olds performed equivalently to adults on certain required components of informed consent, including assimilation of information and awareness of relevant choices (Weithorn & Campbell, 1982). This prompted lower courts to wonder whether patients under the age of majority might, in fact, be able to make their own decisions, ultimately concluding that age "is not an impenetrable barrier that magically precludes a minor from possessing and exercising certain rights normally associated with adulthood" (In re E.G., 1989). The pendulum swung so far to the other side that some commentators argued that "the presumption on the part of physicians…should be that all adolescent patients between 14 and 17 have the capacity to make health care decisions, including end-of-life decisions, except when individual patients demonstrated that they do not have the necessary decision making capacity" (Weir & Peters, 1997).

Granting mid-teenagers the right to make their own medical decisions, however, would seem to overlook universally-recognized traits of adolescence (such as impulsivity and susceptibility to peer influence), which bode poorly for "mature" decision making (Steinberg & Scott, 2003). Extending decisional authority to this group is also a two-edged sword, as it would logically apply to non-medical contexts, as well. If mid-teenagers truly are as capable as adults at making decisions, then they should be held accountable for those decisions in the same way that adults are. This would include punishment for crimes committed prior to achieving the age of majority, which was the Supreme Court's reasoning in upholding the use of the death penalty in murder cases, as long as the defendant was at least 16 years old when the crime was committed (Stanford v. Kentucky, 1989).

Subsequent neurocognitive studies cast doubt on the supposed adult-level maturity of adolescents. Advancing medical technology was able to provide an anatomic explanation for the well-known fact that early adolescents tend to value instant gratification and be less future-oriented. Compared to the limbic (emotional) areas of the brain, adolescents' prefrontal (deliberative) areas are now understood to lag behind in development (Casey et al., 2011). This finding is the basis of the dual-process model of adolescent maturation, which distinguishes between "cold cognitive abilities" (used in calm situations without much peer influence) from "hot cognitive abilities" (used in highly charged, emotional situations). While the former are often in place by mid-adolescence—thus explaining why teenage subjects score roughly equivalent to adults on tests measuring recall of information—the latter take longer to develop, due to delayed myelination of the prefrontal cortex (Steinberg et al., 2009).

This prompted reconsideration of the degree to which adolescents should be held responsible—or be forced to deal with the consequences—of their actions. From a legal perspective, the Supreme Court subsequently ruled that capital punishment for crimes committed while someone was a minor violated the Eighth Amendment's ban on "cruel and unusual punishment" (Roper v. Simmons, 2004). From a medical perspective, greater attention is now devoted to "cooling down" discussions about medical decisions in order to ascertain an adolescent's true values and beliefs. One suggested method of doing so is, rather than confronting an adolescent with the possibility of their own impending death, they could be asked how they would counsel a close friend in a similar situation, thereby hopefully bypassing some of their more emotional or reactionary tendencies (Diekema, 2020).

This nuanced understanding of adolescent decision-making also informs how one should respond to situations where the patient and their parents disagree about a plan of treatment. Certainly, if the parents are refusing a potentially beneficial treatment that the patient is willing to accept, this should prompt concerns for medical neglect and potentially prompt a report to Child Protective Services. More common, though, are situations where the patient is declining treatment that the parents favor, potentially for reasons that suggest they are more focused on the present than on the future (e.g., refusing chemotherapy due to side effects such as hair loss).

Compelling treatment over a patient's refusal is never a trivial matter. For even though this does not constitute overriding the patient's "autonomy"—which the patient is not exercising if the decision is not informed and reflective of their underlying values—it is nevertheless a compromise of their bodily integrity. The relative benefit as well as the frequency of treatment must be considered, with a one-time significantly beneficial treatment easier to justify than ongoing treatment with uncertain efficacy (Macauley, 2018).

Another relevant consideration is the patient's age, especially the time remaining until they reach majority. Indeed, the reason the Illinois Supreme Court upheld the right of a minor to refuse blood transfusions based on her Jehovah's Witness beliefs was she was only six months away from turning 18, at which point her right to refuse would be undebatable (In re E.G., 1989).

One further, often unrecognized nuance involves situations where both the patient and the parents are declining a treatment that the team believes to be potentially beneficial. The burden of proof for medical neglect coupled with the distastefulness of compelling treatment over a patient's objection might well lead to respecting the dual refusal. But here it is important to examine the degree to which the patient's beliefs that are prompting the refusal are influenced by the parents. If there is a strong sense that the patient, left to their own devices, would actually accept the treatment, then further exploration is warranted.

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Family Centered Pediatric Advance Care Planning for Teens Living with HIV and Cancer (FACE-HIV; FACE-TC)

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In the United States in 1994 AIDS had become the leading cause of death for all Americans aged 25-44 years and AIDS deaths for persons aged 13 and older showed a sharp increase.[1] Pediatricians, adolescent medicine clinicians, and families were doing everything in their power to keep children alive, in the hopes that a treatment or cure would soon be found. In contrast, adolescents with advanced AIDS were telling their case managers and nurses that they wanted to stop medical treatments; but not communicating this to their families or doctors. Thus began my journey to find a way to give adolescents a voice in their own end-of-life care; to help families "break the ice" to talk with their teen about death and dying; and to ensure that the first conversation about goals of care was not in the intensive care unit.

Through a process of community based participatory research with key stakeholders (adolescents, their family caregivers, clinicians, researchers, and experts in adult advance care planning), we adapted/developed and tested in five randomized clinical pilot trials (RCTs), disease and culturally specific iterations of the FAmily CEntered pediatric Advance Care Planning (FACE pACP) intervention. These iterative adaptations include: (1) Teens living with HIV (FACE-HIV)[2]; (2) Teens living with Cancer (FACE-TC)[3]; (3) Spanish speaking adolescents living with cancer (FACE-SP)[4]; (4) Children living with rare diseases who are unable to participate in medical decision making (FACE-Rare)[5,6]; and (5) Family caregivers of infants with rare diseases in extended stays in the neonatal intensive care unit (FACE-NICU)[7]. This article will summarize the work with adolescents living with HIV and with cancer.

To begin, our Community Advisory Board of teens living with HIV and their family caregivers adapted with permission an AARP survey of African-Americans and non-African-Americans about end of life care.[8] While administering the adapted survey with a young man who was in a wheelchair because of AIDS related complications, he revealed that he no longer wanted medical interventions. I next administered this IRB approved survey to his mother, who reported that her son wanted everything done. The patient had not told his mother that he had changed his mind. After an ethics consultation to break confidentiality in this research study, I informed the patient's health care provider that the patient no longer wanted treatment. The provider immediately teared up. We grow attached to our patients. The provider arranged for a family meeting, and medical interventions were stopped. This young man died 10 days later. This experience and the results from two pilot randomized clinical trials[9,10] and two multi-stie trials[11,12] using the Lyon Advance Care Planning Survey – Adolescent Version & Surrogate Version revealed two consistent findings: (1) Most families did not know what their adolescents wanted for end-of-life care; and (2) adolescents preferred to have these conversations earlier in the course of their illness, rather than when they were dying.

These findings formed the basis for the collaborative creation of the pACP FACE-HIV and FACE-TC interventions. FACE pACP has three approximately 45 minute sessions administered weekly and facilitated by a trained/certified facilitator. FACE-TC is the only pediatric advance care planning program recognized by the Evidence-Based Cancer Control Programs by the National Cancer Institute.[13]

Session 1.

The Lyon Advance Care Planning Survey is administered separately to the adolescent and chosen surrogate decision maker(s) if the adolescent is age 18 years or older or to the adolescent's legal guardian(s). The survey prepares the adolescent and the family for the kinds of issues that will be discussed in Session 2.

Session 2.

The Respecting Choices Next Steps conversation guide.[13,14] The adult version of this ACP conversation guide was adapted with input from our key stakeholders. There are six stages beginning with the patient's representation of illness and current symptoms. There is a facilitated conversation which always starts with the adolescent and then turns to the surrogate(s) for their understanding. The conversation then moves in a structured way through hopes, fears, what sustains them during difficult times, experiences with hospitalization, experiences with death and dying and how these experiences might guide their medical decision making. There is then a transition to discussion of the end of life treatment preferences with 3-4 hypothetical scenarios.

The Statement of Treatment Preferences did not include discussion of CPR or intubation as more than 90% of all adolescents wanted these interventions. Adolescents were told to assume that they would be kept comfortable in each situation, i.e., pain would be managed. Included scenarios were discussion of (1) a long hospital stay (in the ICU) with complications where the outcome was uncertain; (2) physical disability where the patient would not be able to walk or talk or need 24 hour nursing care; (3) only 3 months to live prefer to be at home or in the hospital; and (4) did not know who you were, where you were, or who you were with, and needed 24 hour nursing care. The adolescent and family are then asked to "teach back" the scenario to ensure understanding before moving onto treatment preferences. Choices were to continue all care because length of life is more important than quality of life; to limit treatments in certain circumstances which are specified; or to stop all interventions because quality of life was more important than length of life. The adolescent is then asked if they want their family to strictly follow their wishes or to give their family "leeway" to do what they think is best at the time, knowing their wishes.

Sesson 3.

The Five Wishes.[15] The adolescent and family return to complete the Five Wishes, a legal document in 46 states in the United States. The adolescent and family together complete the document with the help of the facilitator and are instructed on how to update the document, which is also included in the form itself. The family receives a copy, and a copy is placed in the medical record by the facilitator. The facilitator also emails a copy to the treating physician with a summary of the goals of care conversation.

Inclusion of a legal advance directive was controversial, because we were including a clinical, legal document in a research study. However, an ICU doctor and the family representative on the Internal Review Board (IRB), as well as the attorney for the hospital, all supported the completion of a legal advance directive document, stating that the family should not go through this process and then be unable to complete the legal document. Also, this process was consistent with our hospital policy regarding adolescent advance directives.

To date no adverse events have been reported, as measured by the study specific Satisfaction Questionnaire,[17,18] which was developed during a “Science in the Fishbowl” experience sponsored by NIMH/NIH, at the start of the program development. There are 13 items on a 5 point Likert scale ranging from “It felt hurtful” “It was harmful” to “It was useful” “It was worthwhile”. Families were more likely to report feelings of sadness compared to controls, a normal reaction to discussing the possibility that one’s child might die before you.

The intervention proved feasible and worthwhile.[17,18] Adolescents and families who enrolled consistently attended all three sessions across studies; and with high rates of retention over 18 months post-intervention in the two multi-site RCTs.[19,20] There was one case in which a female adolescent with cancer when asked about her fears responded, “My doctor told me not to think about my fears that that was his job.” The facilitator appropriately asked, “Would you like to stop?” She said, “Yes”, and she and her mother withdrew from the study. This is a good example of consent being moment to moment, and the right of participants to withdraw at any time. Another adolescent boy with cancer stated as they approached the Statement of Treatment Preferences, “I didn’t know I would be talking about me.” His mother then said, “Yes, it’s like you are a guinea pig in an experiment.” The facilitator said, “Would you like to take a break to decide if you want to continue?” They took a break and this 14 year old, sitting up very straight asserted that he wanted to stay in the study. Throughout the Statement of Treatment Preferences he responded, “I want to continue all treatments.” His responses suggest that he felt both empowered to state what he wanted, and perhaps that he had feared that he would be pressured to limit treatments. The FACE pACP intervention is firmly committed to respecting patient preferences, not to an agenda to limit interventions at the end-of-life, if this is what the patient wants. We found no adolescent-family conflict about treatment preferences that required referral to an ethicist for resolution. We did have two cases which led to a referral to the chaplain to process religious beliefs about ACP.

Rigorous, multi-site, RCTs demonstrated consistently across illness groups the following benefits of the FACE pACP intervention for teens, compared to controls: (1) congruence in end-of-life treatment preferences between teens living with HIV or cancer and their families which was sustained for one year in both groups (our primary objective)[19,20]; (2) adolescents living with HIV and cancer were significantly more likely to give their families "leeway" to do what they thought was best, knowing their wishes[2,3,17-20]; (3) families reported less anxiety[21-23] and greater positive appraisal of their caregiving[24]; (4) adolescents living with HIV reported fewer disease specific symptoms at 12-months post-intervention,[20] but this was not replicated for adolescents living with cancer[25]; and (5) documentation of advance directives in the electronic health record at studies' closure.[19,20,26]

Across studies, we have found that for adolescents living with HIV, religiousness modified quality of life outcomes and was more powerful than participation in FACE pACP.[20,27, 28] Secondarily, for we found that the intersectionality of gender and poverty was associated with increased symptom suffering among female adolescents living with cancer.[29]

An unexpected finding was that among 125 ineligible adolescents living with HIV/AIDS, 62 (50%) were ineligible because they could not identify a surrogate decision-maker they trusted enough to make decisions for them.[30] Future palliative care research should be extended to "unbefriended" adolescents who do not have supportive family relationships.

The structure of the FACE pACP intervention safely broke the taboo about discussing death and dying and end-of life-treatment preferences with seriously ill adolescents. Benefits were realized specific to the hypotheses. Compared to controls, FACE pACP (1) adolescents were willing and able to give voice to their end-of-life treatment preferences to their families in a supported and structured conversation; (2) families were willing and able to talk with their teens about end-of-life treatment preferences and to honor their choices; (3) clinicians received the a copy of the Statement of Treatment Preferences and of the Five Wishes advance directive; and (4) these documents were placed in the medical record and locatable at study closure. Furthermore, even as adolescents changed their treatment preferences over time, compared to controls, adolescents and their families in FACE pACP maintained congruence for one year after the intervention.

Implementation of this evidence-based approach with seriously ill adolescents receiving care in pediatric tertiary and quaternary hospital-based clinics is the remaining challenge.

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Concurrent Care: When an Adolescent Becomes an Adult

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Children are often vulnerable when facing medical challenges and regulations. Concurrent care for children helps to provide some form of protection for pediatric patients. It enables those with life-threatening conditions to receive both curative and hospice care at the same time unlike their adult counterparts. Since the induction of the concurrent care model, as established by the Affordable Care Act, in 2010, all state Medicaid programs are mandated to provide this service to all children under the age of 21. Most private insurance agencies hold the same understanding noting the program's benefits. Nevertheless, one must wonder what becomes of those children who reach the age of 21 and must then choose to either continue curative care and forfeit their hospice care benefits or vice versa. This is due to the fact that concurrent care may unexpectedly lead to a catch 22 for this particular subset of patients. It is widely understood that many children receiving hospice care and disease-modifying therapies together survive longer than their expected prognosis (Steinhorn, Kuchar, & Lindley, 2023). Financial considerations become more relevant as resources are further utilized. How an insurance agency chooses to evaluate this reality, as well as how a provider chooses to handle the overall change, either as a whole or on a case-by-case basis, plays a role in the finality of care distribution.

Hospice Provider Case

The patient presented to our hospice service was nearly 21 years of age. He suffered from metastatic osteosarcoma (malignant bone cancer) from the age of 17 and received multiple surgical and chemotherapeutic interventions with little response. He demonstrated increased pain and respiratory symptoms two days prior and then presented to the pediatric hematology and oncology (PHO) clinic for support. He was given the opportunity to enter a new trial for his disease, but he appropriately declined and returned back home with increased oral pain medication. His pain quickly became more severe, and he lost his ability to swallow medications and hospice was appropriately contacted. He was admitted to our inpatient hospice unit (IPU) from home in order to receive IV Dilaudid via his computerized ambulatory delivery system (CADD pump) which he tolerated well over the course of three days. However, he eventually turned 21 and was no longer covered under the concurrent care rule. His particular insurance agency had the right to terminate his care based on his age. This understanding imposed significant hardship in that his family lacked sufficient funds to addressing the issue through a self-pay model. It was deemed futile to consider sending him back home under his condition and a decision to petition his insurance agency in order to continue his care was made.

Considering Other Relevant Factors

There is a critical need to understand 20-year-old patients in concurrent hospice care before transitioning their end-of-life care (Mooney-Doyle, et al., 36). One must take in consideration that children living either in rural or more impoverished areas tend to receive insufficient hospice care as compared to their peers. The possibility of finding an available adult provider to assume a smooth transition is difficult. Furthermore, 20-year-old patients have other issues that can impede the success of an adult transition. Many of them have several comorbid conditions including diabetes and asthma, deal with mental and behavioral issues, and often are dependent on complex equipment to assure their stability (38). Although adult hospice services mainly preclude patients from receiving care that is often aligned within hospital settings, this does not mean that general medical concerns and conditions should not receive attention. Lastly, conversations between hospice care and insurance providers should occur before the transition is to take place. This in turn will allow for open discussion regarding which services might exist for a patient after his or her transition is made (39).

Patient Case Revisited

Much to the appreciation of both the patient, his family, and our hospice team members, the petitioned insurance group agreed to continue his inpatient payments. The decision to put forth the needs of a particular patient over the assumed age limitation understood by the concurrent care rule was just in its application. Although a positive response is not likely for all cases, the relevance for providers to promote best care options for each patient still resounds. Our staff's advocacy allowed this young man to retain the care that he desperately needed within a dignified inpatient setting, while also allowing for improved control of both his level of pain and anxiety.

Conclusions

It behooves all health care providers to understand in depth the relevance of concurrent care as it relates to hospice and children. Although beneficial in many ways, such as allowing for curative treatment options, it is still limited to those individuals under the age of 21. A future in which all individuals regardless of their age have the right to concurrent care seems appropriate. However, this seems unlikely at this time for several reasons including financial restraints. Nevertheless, medical providers have often assumed a leading role for patient advocacy when necessary and within the context of appropriate circumstances. One might think that seeking continual concurrent care for a newly turned 21-year-old fits the definition of appropriate use of resources and is simply the just thing to do.

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Anticipatory Grief and Bereavement for Children, Teens, and Families

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Life goes on for each of us often with many commitments to family, work, school, and life in general. Suddenly, all that can change in an instant. A traumatic accident, a new diagnosis, recurrence of a prior diagnosis, or a life-altering event such as a stroke or heart attack. These are just a few examples of events that can alter our lives and the lives of those we love in an instant. "Children and families will often begin the process of anticipatory grief at the time of diagnosis."[1] As the process unfolds, it is essential for the Pediatric Palliative Care team to communicate with the patient and family to address concerns related to these ongoing losses and the experiences they create for this child and family. These ongoing losses may impact goals of care. They may lead to reflection and re-goaling to meet the changings needs and perspective on quality of life for this patient and family.

Anticipatory grief may be one of the first reactions to a new diagnosis or any of these events previously mentioned. "Patient responses and those of the family members to receiving bad news range from shock, disbelief, and denial to anger and fatalism."[2] These reactions may include thoughts, behaviors, feelings, and emotions. These reactions may be impacted by one's culture, belief system, family support, community, past experiences, and developmental level. In pediatrics, children/teens may not be able always to verbally express themselves. Perhaps involving some creative media such as drawing, writing, or play, may allow a means for them to process these emotions and the impact this news. Consider the developmental stage to gain a better understanding and perspective.

"Anticipatory grief and bereavement—the before, during, and after loss—begin at the time of the child's diagnosis and extend years after the child's death."[3] Grief can disrupt a sense of meaning and stability anticipated at each developmental stage. Thus, a regression to prior stages for understanding may complicate the sense of loss. Suggested communication at different developmental stages may be helpful as coping strategies. As the child, teen, and family process this news, it is important for team members to talk with children and families to allow expression and processing about the ongoing losses they are experiencing.[4]

Developmental Stages and Grief in Children and Teens

Age	Basic Conflict	Concept of Death	Communication Strategies
Birth-18 months Infant	Trust vs. Mistrust	Infant is reactive to the stress. No sense of death or finality.	Provide comforting care, soothing communication
2-3 Years Early Childhood	Autonomy vs. Shame and Doubt	Child may feel the death is their fault or a punishment. They may think of death as reversible.	Utilize play and storytelling, soothing communication, music.
3-5 Years Preschool	Initiative vs. guilt	Magical thinking in this stage. Views death as temporary. Many questions and curiosity.	Use simple concrete language, play, & discussing what they have shared in a safe non-judgmental space.
6-11 Years School Age	Industry vs. Inferiority	Children begin to think more logically. Death is permanent. Sometimes they feel responsible for the illness or death.	Balance honesty and family led details. Any question is OK, provide a safe space, routines are helpful. Art, books, journaling. Reinforce they did nothing wrong.
12-18 Years Adolescent	Identity vs. Role Confusion	This is a time to explore who they are in the world. Death of a loved one can impact that confusion. Anger may be present.	May develop a more mature understanding of the death. Encourage open dialogue and peer support to express grief. Confide in an adult, friend, counselor.

Adapted Combined Resources 1, 4 & 5

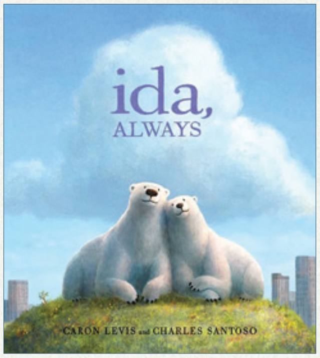
"An understanding of age-appropriate grief reactions and conceptions of death is important when assessing a child's response to terminal illness and a loved one's death."[5] Over time, a child or teen's concept of a new diagnosis, traumatic event, or death of a loved one, for example, may evolve based on developmental stage and new perspectives of the event as it directly impacts them. "The two most important predictive factors of a child's successful outcome after suffering a loss are the availability of one significant adult and the provision of a safe physical and emotional environment."[5]

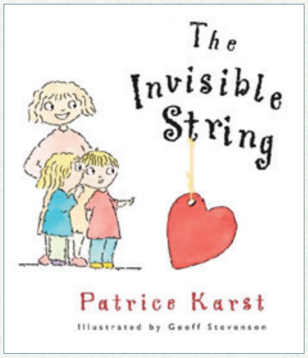
Anticipatory grief in children can be seen as "the reactions, including thoughts, feelings, and behaviors, one has while expecting a loss."[4] Seeking assistance from a child life specialist can be an important member of the interdisciplinary care team in working with children based on their developmental stage. Play is a child's best expression of communication and meaning. Include the chaplain if the family desires. Lean in with compassionate presence. Attentive listening and supportive presence can allow patients and families to process many emotions they may be facing at this time in a unique and personal way. Developing a trusting relationship can be a powerful bridge of support and hope in accompanying them on their journey. Meet them where they are and allow for unique styles of grieving, expression, and coping. In pediatrics, the developmental stage is important to consider to gain some perspective on their viewpoint and understand how this news impacts them and their family.

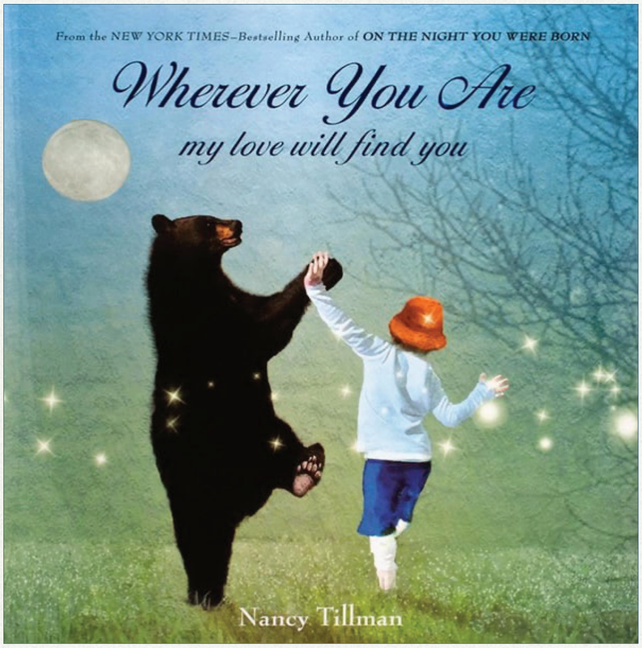
Be attentive to listening for the needs of our patients and families. What have been sources of strength for them in difficult moments? How may the interdisciplinary team work together to address these needs and help them develop support as they move forward in this journey? Careful consideration and respect must be given to each patient and family with humble curiosity and cultural humility. The illness experience may challenge the beliefs and search for meaning of many children and parents at times leading to significant spiritual suffering"[6] Allow the patient and family to share their fears and hopes in a safe place without judgement or fear. Reinforce that the team desires to support their wishes and goals in relation to the situation at hand. Understanding goals of care for the patient and family facilitates the plan of care to move forward in an effort to best meet the needs of the beloved child/family with great respect and dignity. "Pediatric palliative and hospice care (PPHC) is multifaceted care that focuses on a child's and family's well-being along a physical, psychological, emotional, spiritual, and social continuum."[1] Teens, the "forgotten grievers "must be supported well.

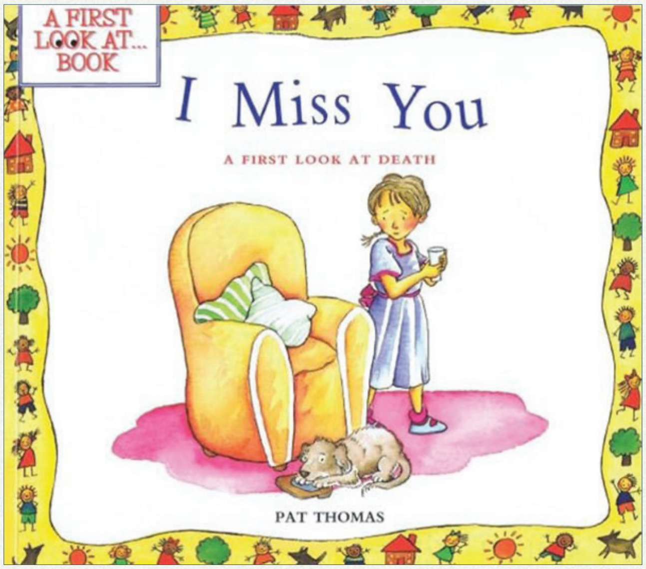
Some Books for Grief and Bereavement Support for Children

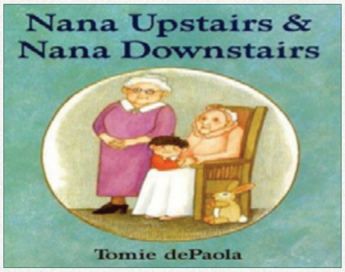
Below are some books to assist parents in providing grief and bereavement support for their children and teens. "These books are valuable resources for talking to children about love, illness, death, and the stages of grief—all of which are abstract concepts that can be difficult for children, especially young ones, to grasp."[7] This can open up conversation for a child's questions and opportunity for discussion.

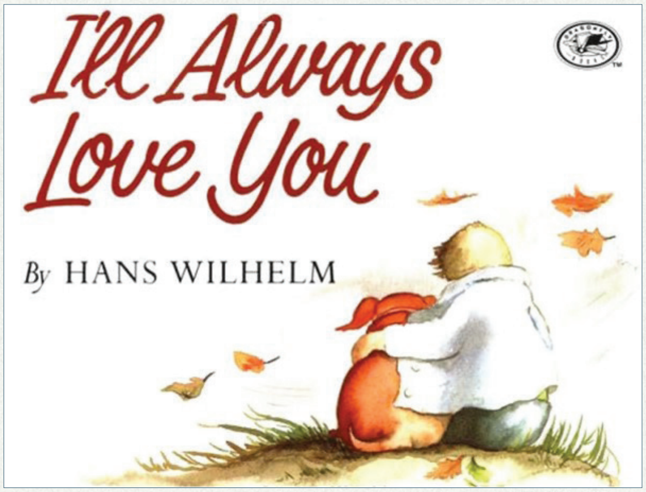


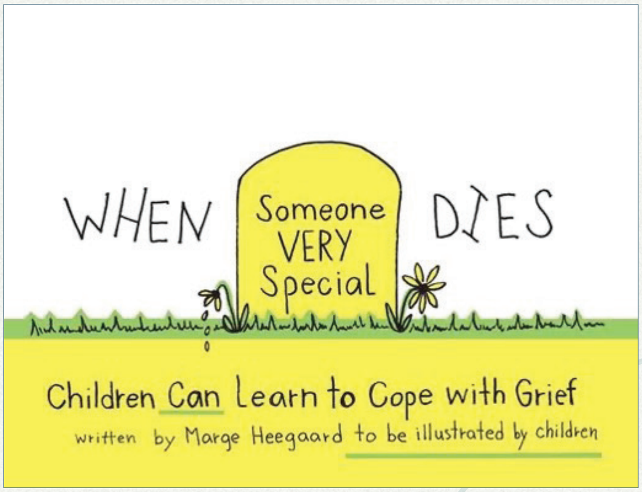












This is a book which provides an opportunity for the children to participate with illustrations.

Some Books for Grief and Bereavement Support for Teens

***I Will Remember You: What to do when someone you love dies: A Guidebook Through Grief for Teens* by Laura Dower,** published 2001. “Each chapter in this guide can help you explore a different aspect of grief. You’ll read personal stories of death and life from real teens like you; advice from a renowned grief counselor; and dozens of hands-on creative exercises to help you move through you own pain and sorrow…into tomorrow.”[7]

***Straight Talk About Death for Teenagers: How to Cope with Losing Someone You Love* by Earl A. Grollman:** This book is a valuable resource which offers guidance for navigating complex pressures of adolescence as well as the trauma of losing a loved one. This is an informative guide for coping with grief in a helpful manner.

***It Won’t Ever Be the Same: A Teen’s Guide to Grief and Grieving* by Korie Leigh:** This 2024 guide, specifically for teenagers helps them to name, articulate, and give meaning to their feelings of grief. It is helpful for those experiencing grief for the first time or those who have experienced it before.

***The Grieving Teen: A Guide for Teenagers and Their Friends* by Helen Fitzgerald:** This guide offers tools to help teens work through their pain with great care and compassion. Addresses many topics from preparing for a funeral to coping with grief on the first anniversary of a death. Addresses many emotions which may be expressed through the journey of grief.

***Healing Your Grieving Heart for Teens: 100 Practical Ideas* by Alan D. Wolfelt:** Practical ideas for supportive activities and action steps to help teens embrace the feelings of loss of a beloved in a healthy way. This book clearly demonstrates that grief is a normal process. Mourning is necessary for healing and we must find ways, activities/ideas to best heal our heart.

Grief Resources for Children, Teens and Families

Judi’s house JAG Institute

For Grieving Children and Families
2025 Childhood Bereavement in the United States
https://youtu.be/4I7qPVuG6Ss?si=fU1cV29GiGRXh_g9&t=1/

National Alliance for CHILDREN’S GRIEF- NACG.org/

“The Alliance is a national organization of professionals dedicated to supporting children and the networks and communities surrounding them.”

Dougy Center- Dougy.org/National Grief Center for Children & Families:

Dougy Center provides support in a safe place where children, teens, young adults, and families who are grieving can share their experiences before and after a death. We provide support and training locally, nationally, and internationally to individuals and organizations seeking to assist children in grief.

Association for Death Education and Counseling-ADEC.org/

“The Association for Death Education and Counseling®, The Thanatology Association®, is one of the first interdisciplinary organizations in the field of dying, death and bereavement, The primary goal of ADEC is to enhance the ability of professionals to meet the needs of those with whom they work in death education and grief counseling”

Compassionate Friends-www.compassionatefriends.org/

The Compassionate Friends offers friendship, understanding, and hope to families grieving the death of a child at any age from any cause.

Courageous Parents Network https//courageousparentsnetwork.org/

Courageous Parents Network (CPN) presents educational resources in an array of formats with a singular goal: to give parents confidence that they are being the best possible advocate for their child.

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4. ADEC Webinar- Supporting Grieving Children: Compassionate Care for Anticipatory Loss- Presented by Jillian Blueford, PhD on November 19, 2024. Accessed September 20, 2025.
5. Himebauch, A, Arnold, RM, May, C. “Pediatric Fast Facts and Concepts #3.” Published on December 4, 2024. https://www.mypcnow.org/fast-fact/grief-in-children-and-developmental-concepts-of-death/
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7. Dower, L. I Will Remember You: What to do when someone you love dies: A Guidebook Through Grief for Teens. Published by Scholastics Inc. 2001.

Readers' Corner

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Weaver MD, Smith SM, Torkildson C, et al. The State of Pediatric Concurrent Hospice Care in the United States. *Pediatrics* 2025;156(3). e2025071610

Summary:

The goal of this article is to quantify and describe the use of concurrent care (CC), including the barriers and benefits perceived by community based US hospice organizations.

What is the current status of use of CC in the US?

- Of the ¾ of hospices who admit children, an average of 38% of the children are admitted under CC
- Challenges and barriers to the use of CC included
  - Complexity of CC leading to confusion, inconsistency, and cumbersomeness.
  - Inadequate use of the appropriate codes
  - Focus on location and access to treatments with less focus on services
  - Inadequate attention to goals of care
  - Poor communication between caregivers, and between caregivers and family
  - In addition to the challenges in implementing a needed support for the patient and family, the entire program is at risk for decreased funding or entire discontinuation

- Successes of CC
  - o Improved family support for children with medical complexity (CMC)
  - o Increased ability to care for the child at home
  - o Increased symptom management and quality of life
  - o Less family stress and improved relationships

Where do we from here?

- Educate hospices about use and benefits of CC
  - Emphasize differences between billing for adults and children under CC
  - Improve the understanding about CC and its optimal usage
  - Improve communication between the hospice and medical teams, especially about which team is directing what service
  - Remind hospices that concurrent hospice care for children is more financially beneficial than standard hospice care
- Use the data from this study as you strive to protect CC, as loss of this benefit will negatively impact the child and the family.

Items of Interest!

Please help us keep the items of interest up to date. Share your news, upcoming conferences or webinars. Are there particular podcasts that may be of interest to our readers? Send any items of interest to Christy at Christy.Torkildson@gcu.edu**. Thank you.**

1. **An educational opportunity to help staff care for pediatric patients** can be found HERE
2. **A wonderful resource that may be helpful is "Not if, but When),** a website that "encourage and support sharing good books and stories about death and loss with children and teens throughout their lives." Website: https://www.notifbutwhen.org/
3. **University of California, San Francisco (UCSF)** hosts monthly FREE webinars. More information can be found HERE.
4. **Pediatric Palliative Care Webinar Series for 2026 registration opens soon!** Calendar and more information, including how to register can be found at https://www.ppcwebinars.org/
5. **AAHPM & HPNA Annual Assembly 2026** will be in San Diego, California March 4-7, 2026-. Click HERE for more information.
6. **ELNEC has several upcoming courses;** if you are faculty, you can get free access to the curriculum for your program/courses you teach. Click HERE for more information.
7. **Have a conference to submit/share** – send us the information to Christy.Torkildson@gcu.edu.
8. **Courageous Parents Network** provides opportunities for our network of caregivers, clinicians, and others to come together to learn about topics relevant to the shared journey. They host webinars with leaders of the field and parents who have been or still are on their journey. There is a wealth of resources for family members and providers. Click HERE for more information.
9. **Academy Health: Enhancing Systems of Care for Children with Medical Complexity Newsletter** is a collaborative project with the University of San Francisco, Family Voices, Boston Children's Hospital, Patient Insight Institute, Patient Advocate Foundation. More information can be found HERE.
10. **The Lucille Packard Foundation for Children's Health publishes the Children and Youth with Special Health Care Needs Network Newsletter** – includes news, policy updates, resources, events, and advocacy opportunities from across the nation. You can subscribe to the newsletter by clicking HERE.

Are there any Items of Interest you would like to share, are there resources that you love? Please email Christy at Christy.Torkildson@gcu.edu

National Alliance for Care at Home

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