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FOR LAYLA: RECLAIMING PURPOSE THROUGH SERVICE, HUMILITY, AND EMPATHY IN HEALTHCARE

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Layla sat in her mother's lap. She looked up at us with bright eyes. From initial glances, Layla appeared to be a happy three-year-old. She made eye contact with us but would otherwise intermittently bury her face in her mother's arm. Her mother provided comfort to Layla, but she was clearly curious who we were among the various teams their family had met. We introduced ourselves to Layla and her parents – the pediatric palliative care team.

We're a team that consists of doctors, nurses, social workers, and chaplains with diverse training, experiences, and skillsets that lend to unique perspectives. When united, our differences broaden our understanding of the family's goals and values. We're a team of healthcare providers who each self-selected to specialize in palliative care after being called to the tenderness and vulnerability of the work. We're a team whose purpose is to develop rapport and understanding through a commitment to empathy, humility, and service. Such a mission statement is undoubtedly overwhelming. Stated more simply, as we described to Layla's parents, our hope is to serve as a supportive care team to families while they navigate medical complexities.

We inquired if now was a good time to meet with Layla's family. Her parents nodded. Their agreement to meet with our team was not always the norm. The idea of "palliative care", particularly for a child, was often the last thing parents anticipated, let alone welcomed. On occasion, the introduction was the extent of our visit, with parents declining after asserting their intentions of wanting to "do everything" and "never stop fighting". Such statements often provided us clues to their concerns related to our team's intent, yet our hope is always to align and give voice to their values and goals – including when it is to "do everything" and "never stop fighting". We have overcome hesitations to our team through gentler paced education, validation, and patience. At times, we've also pulled back when boundaries are resolutely drawn, and guards are firmly raised. In such situations, we offer ongoing availability and hope to be invited back.

We pulled up chairs to sit alongside Layla and her parents, mirrored their body language, and engaged with curiosity. We introduced our team members and then asked Layla's parents to share what the medical chart couldn't tell us – who they are as a family and who Layla is as a person. As her parents took turns sharing their family's story, we heard the heartache. They described their relationship, building upon their shared passion for boating, camping, and hunting. They shared their long, difficult journey to have children, and the overwhelming excitement of having a son and now Layla. They shared how Layla loves her brother, the family dog, and all things purple. They identified that Layla had an uncomplicated birth, and her development progressed as typical. Yet, they began to worry when Layla began having issues with feeding and reaching milestones. Her health took a turn for the worse when they noted difficulty breathing, which prompted the trip to the hospital. They admitted the guilt of not knowing to push for a work-up prior to the current admission, as well as the pain of now watching her endure so many evaluations without concrete answers.

Layla's parents also shared the difficulties of balancing time at home with Layla's older brother, who would soon be starting school, and being present at the hospital to support Layla and each other. Our team continued to listen. Her parents were aware of the resources available to help support them at home as well as at the hospital. They weren't asking for more resources. They simply wanted a chance to speak about their worries and have someone hold the tension of their days while acknowledging the difficulty of their experience.

We asked about their understanding of Layla's medical condition, as well as their anticipated plan for the coming days. We inquired about this to ensure decision-making was anchored in their medical understanding and their family's values for Layla's current and future quality of life. In this regard, our empathy actively guided our purpose and provided clarity around the role of the team.

They identified that the recent genetic diagnosis provided relatively little plan or trajectory for Layla. They shared the heartbreaking facts – Layla's future remains unknown. Her life expectancy may be months to years with the ongoing potential for acute life-threatening events, much like the one that led to the current hospitalization. The family shared the spectrum which may exist for Layla and the frequently uttered line of "time will tell". With this uncertainty, our team's continued purpose was to support Layla and her family through service. We walk alongside families, not because we hold the answers but rather to empathetically and humbly serve their needs over time. We support and validate as they consider opportunities to honor Layla and her life, weighing future interventions, and prioritizing comfort over milestones.

As our team held silence with them, Layla's mother began to shed tears and looked to her husband. We allowed her time and space, and soon she opened up about how difficult it had been. She admitted, "It's hard to feel, let alone say out loud, but I am angry that no one can give Layla a diagnosis with a treatment to help her." She paused and added, "I'm just exhausted." Layla's father nodded in agreement, then shared, "If I could take her place, I would." They both reflected on what was important to them as parents and as a family. Through teary eyes, they shared their hopes for Layla to have a fulfilled life, playing and laughing alongside her older brother and their family dog. They smiled as they described the things they enjoy doing as a family. We continued to listen.

Supporting Layla and her family demanded that we lean into their experience. That was empathy in action. It required curiosity and authenticity to feel alongside Layla's parents the full range of their emotions. To do this, it remained imperative that we remembered that this was their story, not our own. Together, as a team, we held this uncertainty without agenda or judgement. We asked questions to understand what has influenced the lens of their perspective – their experiences, values, and faith, including their quiet hopes and deepest worries.

We recognized there were no easy answers. No innovative options for tests, scans, or treatments. However, in our time with Layla and her parents, we provided them with the space and permission to have hard conversations, both with each other and in collaboration with our team. As we closed our pediatric palliative care consult, we shared our commitment to supporting them throughout Layla's life – being their cheerleader to celebrate the wins and a shoulder for the heavier moments. We thanked them for being vulnerable with us and let them know we would be back to visit, although always available.

As we stepped away from this interaction and headed onto our next consult, we refocused on the shared objective to ensure goal-concordant, values-based, family-centered care. As a team, we have learned to acknowledge the emotional toll these repeated, deliberate conversations can have on individual and collective professional sustainability. To mediate the impact, we have adopted practices to process experiences and emotions, while carrying forward lessons learned. Although we may not always have the answers, our team maintains a shared purpose – to humbly and empathically serve families facing medical complexity with their children. ■

Biographical Notes

Carolyn Mueller, DSW, LICSW, is the social worker on the pediatric palliative care team at Mayo Clinic in Rochester, Minnesota, where she also directs the Children's Bereavement Program. She holds an academic appointment as an Instructor of Social Work at Mayo Clinic and serves as an Assistant Professor of Social Work at Winona State University. Her professional focus includes pediatric palliative and bereavement care, bioethics and moral distress, and interdisciplinary collaboration in healthcare settings.

Aubrey Manahan, RN, CHPPN, is the inaugural registered nurse on the pediatric palliative care team at Mayo Clinic in Rochester, Minnesota, bringing over 19 years of pediatric nursing experience in both inpatient and outpatient care. She is a Silver Level Quality Academy Fellow and a HELP Program–trained peer supporter. Aubrey holds an academic appointment as an Instructor of Nursing at Mayo Clinic and is recognized for her contributions in pediatric bereavement care at Mayo Clinic.

Amy Crowley, RN, BSN, is a registered nurse on the pediatric palliative care team at Mayo Clinic in Rochester, Minnesota, with more than 35 years of experience caring for pediatric patients in the ambulatory, inpatient, hospice, and palliative care settings. She is a HELP Program–trained peer supporter and a Magnet Champion with the Department of Nursing. She holds an academic appointment as an Instructor of Nursing at Mayo Clinic.