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MANAGING ESTRANGED RELATIONSHIPS AT THE END OF LIFE

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CASE DESCRIPTION

"There is so much love in this room," hospice nurse Martha said almost immediately following our introductions as two of the hospice team members that would be caring for Cheryl and her family. "I'm Cory, Dr. Cory Ingram, it is a pleasure to meet all of you," I had offered. I asked, "Cheryl, who is visiting you today?" "This is my husband, Randy, and in laws, Randy's parents, Doris and Larry and my brother and sister-in-law Mike and Judy. "This is my wife, Michelle, and Judy's husband, Bob," Mike explained. They were all very upbeat and it would have been hard to imagine for an outsider that Cheryl, age 48, was likely in the last two weeks of life having just decided to discontinue hemodialysis due to the progressive nature of her lung cancer, despite treatments.

"They are all visiting from Mantorville where Randy and I grew up, just down the street from each other", Cheryl added. Nurse Martha, interested to learn more about Cheryl and all that was important to her, inquired about her side of the family. "My parents live in the same house I grew up in, just down the street from Doris and Larry, and have for the last 53 years." Cheryl added. "We look forward to meeting them

when they visit," nurse Martha offered. "Oh, they won't be visiting, we haven't spoken in the last eight years; not even since I've been ill," Cheryl said matter-of-factly.

In the process of getting to know Cheryl and her family we had come to learn that Cheryl had an estranged relationship with her parents. In all honesty, our hospice team's gut reaction is to look for avenues to repair that estranged relationship. Over the next 48 hours we probed, "How about if we reach out to them? We could give them a call and facilitate a conversation? We could include your minister if that would be helpful." Cheryl was gradually slipping naturally into the familiar and common state of dying hallmarked by sleeping more, eating less, and communicating less as well. We asked ourselves how best our team could help Cheryl and her family.

As members of an inpatient hospice team, we have come to identify a common theme, albeit infrequent, that raises specific challenges in providing end of life care – estranged relationships of birth family members, without any patient desire for rapprochement.

DISCUSSION

As hospice providers we consider the patient and the family as the unit of care. We provide bereavement support to the bereft. Our experience in providing end of life care to patients who identify an estrangement of a sibling or a parent who won't allow contact or attempt rapprochement can be difficult for our team. For some team members, these situations may lend to the experience of moral distress. It almost feels like we are failing the patient and the family by not finding an opportunity for reunion. We feel like we are failing because we are unable to facilitate the patient dying well with nothing left unsaid or undone.[1] We are failing because we are unable to create an opportunity for the things that matter most to be said before they are forced to say goodbye forever.[2]

In reflecting on the care we provide, and the experience of patients and families, we have developed a framework that may be useful to other clinical teams attempting to foster rapprochement when all efforts are being thwarted by the parties involved.

We devised a four-category approach to aid hospice teams in how they may choose to approach patients and families in estranged relationships. The first category is *Ceased Relationships*. These are the relationships that have ended prior to the dying phase and approaching end of life. The second category is *Ceasing Relationships*. These are relationships the patient identifies as relationships that simply need to be ceased but for many reasons have yet to be formally ended. We often find the patient not having the energy and/or desire to address these *Ceased* or *Ceasing Relationships*. We propose that clinical teams should follow the patient's lead in these situations. So, our recommendation is to affirm, accept, and normalize ceased and ceasing relationships as a normal part of life. Further attempts may actually strain

your relationship with the patient or even worsen their end-of-life experience. *Ceased and ceasing relationships* are already over and past the point of repair.

Often the patients will want to focus their energy on relationships in our third and fourth categories in our framework. These are two categories that most likely capture the interest and energy of your patient and are also most likely to allow your hospice team to provide the support that you will be most successful in providing. These last two categories are the *Healing Relationship* and the *Celebrating Relationship*. *Healing Relationship* describes relationships that are in need and desire of rapprochement. *Celebrating Relationship* highlights those relationships that are whole and without anything left unsaid or undone in advance of the end of life. These relationships need celebrating and likely are being celebrated without much effort on the part of our teams.

When we meet with patients near the end of life it is possible that we will find them with relationships in all categories of our framework. They will have some relationships that have ended, some that need to end, some that need mending and some that are just fine the way they are. So how do we tailor our approach to each and every patient with humble regard for their whole person well-being? We suggest that in our partial roles as historians, counselors, clergy, and guides we start with active listening. Simply listening to their story and accompanying them as they share, and we solicit their story with tentative questioning to better understand their story and their experience. Stories will have characters and their life story will start to reveal the relationships in their life that are important. The relationship between them and their family members and friends. It may become apparent which relationships are ceased, ceasing, healing, or in need of celebration.

For relationships that are ceased and ceasing, perhaps our best approach is simply to listen and accompany. Perhaps bearing witness is the best therapy. For relationships in need of healing our role as counselor can also be augmented by our role as guides. In this unique role, addressing the healing relationship, we have the opportunity to guide the patient by offering the four things that matter most as a method of rapprochement that they may be able to use or request that you use in helping them heal that relationship that is meaningful to them.[2] The four things that matter most are: please forgive me, I forgive you, thank you, and I love you. Along these same lines, elements of existential distress may certainly arise and in your partial role as clergy, you can provide active listening, presence, and accompaniment to the scope of your particular discipline. For relationships in need of celebration, our role is largely to facilitate the environment for that to happen and find out how best to dose our involvement recognizing we may not be needed at all, and that is ok.

Balfour Mount wrote years ago of our roles in creating a space for healing and we believe that is the work of our team.[3] We hope that by identifying and categorizing the relationships as ceased, ceasing, healing

and celebrating that hospice teams can better tailor their interventions to support the patient and their relationships near the end of life.

OUR APPROACH

What we failed to recognize is that Cheryl was at peace with the relationships of her life. Instead of feeling moral distress we had an opportunity to recognize that there was nothing left unsaid or undone in the setting of a ceased relationship. After 48 hours of fruitless probing, I finally inquired, “Cheryl, thank you for giving us a glimpse into what is most important to you right now. If it is ok with you I just want to clarify what I am hearing in regard to your relationship with your parents, is that ok?” “Sure.” “What I am hearing is that the relationship with your parents ended some time ago and currently your energy is focused on other relationships you would like to celebrate. Did I get that right?” I asked. “That’s right,” Cheryl confirmed. “Thank you for the clarification, Cheryl. We appreciate knowing how best we can help you and we’ll focus on celebrating the relationships that are most important to you. You keep us posted if there is anything else our team can help you with during these precious times.”■

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Biographical note

Cory Ingram, M.D., M.S., FAAHPM, is a Hospice and Palliative Care Consultant at Mayo Clinic. Dr. Ingram is the Director of Quality for Mayo Clinic Hospice and the Quality and Safety Curriculum of the Hospice and Palliative Medicine Fellowship. Dr. Ingram also shares his expertise through teaching as an assistant professor of both Palliative Medicine and Family Medicine with the Mayo Clinic College of Medicine and Science and a Co-Director of Communication in Healthcare in the Program for Professionalism and Values. Dr. Ingram is a fellow of the American Academy of Hospice and Palliative Medicine and has served in multiple capacities in the humanities and is the Editor in Chief of the AAHPM Quarterly and in his tenure, they are launching an Artist in Residency section to the publication. He has been featured at the Canadian Virtual Hospice and holds Storytelling workshops with Canadian health care institutions. Dr. Ingram is currently working with the palliative care units in Ottawa using the 55-Word story as a modality to improve meaning, purpose and quality of life. Dr. Ingram is also completing his Narrative Medicine Certificate from the University of Toronto Narrative-Based Medicine Lab and is working on a long form documentary photographic and narrative medicine project on caregiving through the end of life to complement his

transitional caregiving research. Dr. Ingram is also co-author and collaborator on a forthcoming book focused on ethical care of the frail elderly in Europe and North American and a published photographer and poet.

Martha Siska, R.N., is a Hospice Care Coordinator for Mayo Clinic Hospice in Rochester, MN. She received her BSN from the College of St Teresa in Winona MN. She has enjoyed a wide variety of positions in her 45-year career at Mayo Clinic. She provided direct patient care for 30 years both in the Coronary Intensive Care Unit and later in the Neurosurgical Intensive Care Unit. She enjoyed the role of Nurse Manager of the Coronary Intensive Care Unit for over nine years. She went on to hold positions as Educator in Infection Prevention and Control, RN Extender for the Cardiovascular Services, and Case Manager for Mayo Clinic Health Services before joining the Mayo Clinic Hospice team in 2017 as a Hospice RN Care Coordinator. Martha has provided numerous formal presentations on hospice level of care to groups of patients and their families, medical residents and hospital-based nursing care teams. She has received the Service Excellence Award and the Karis Award. She has coauthored articles during her time in Infection Prevention and Control. Publications relevant to her experience in hospice care include: *Music Therapy Intervention to Reduce Caregiver Distress at End of Life: A Feasibility Study*.