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Commentary

The Impact of Family Dynamics on Palliative Care at the End-of-Life

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ABSTRACT

This commentary is the second in a series highlighting the challenges we face in providing palliative care. This case highlights the numerous, multifaceted issues that interplay in the complex web of physical and psycho-social dynamics that are always present but take on more significance towards the end of life. The rationale for documenting our experience, undoubtedly a shared experience among palliative care teams, is twofold: (1) as a form of narrative reflective debriefing and (2) to give context to the distress that we see manifested by families as a loved one enters the end-of-life (EoL) period.

Keywords
Palliative care; Familial dynamics; Distress; End-of-life (EoL).

CASE EXPERIENCE

This 50-year-old gentleman was diagnosed with carcinoma of the bowel in 2020, which was initially treated with resection of the primary tumor. The multidisciplinary team (MDT) recommendation at that time was for the completion of surgery and chemotherapy, which the patient declined. He was unable to follow-up at our facility after seeking multiple medical opinions abroad. On his return to our oncology team, imaging then demonstrated multiple progressions despite systemic chemotherapy. He required multiple hospital admissions during 2023 for poorly controlled pain, which was consistent with extensive intra-abdominal lymphadenopathy, including celiac nodes, peritoneal nodes, and omental nodes. He developed jaundice, which was refractory to biliary stenting and required right-sided video-assisted thoracoscopic surgery (VATS) for pleural biopsy and talc pleurodesis to optimize his symptom control.[1]

By late 2023, he had deteriorated significantly. His liver enzymes were rising, and his physical function was worse; he was now only capable of limited self-care and spent more than 50% of his waking hours in bed. The recommendation from the oncology MDT meeting at this point was for palliative systemic therapy with dose reduction to reduce toxicity. He traveled abroad again at this point but returned after only a few weeks in a precarious physical state, emaciated, severely jaundiced, and now bed-bound and fully dependent on all his care needs. At this point, approximately five weeks before his death, he was admitted under the care of the palliative care team for end-of-life care, and an allow natural death (AND) status was agreed upon following discussion with the family.

During our earlier interactions with the patient, we noticed that he was not accompanied by any family members, either during his chemotherapy sessions, clinic appointments, or inpatient admissions. We broached this issue with him, and he explained that he did not want to put any pressure on his wife but agreed that, at the very least, he should discuss this with his son and his brothers. Unfortunately, he did not do this, and on his return from Singapore (where he received chemotherapy), his family found out about his longstanding malignancy. The family was understandably extremely angry that this information had been kept from them, and his brothers formally complained that we should have broken the patient's confidence and told his family about the diagnosis of cancer.

There were significant family dynamics at play, which complicated his care on the ward. His wife and brother-in-law

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(his wife's brother) prevented nurses from administering the required injections of morphine and turned off his morphine infusion pump on multiple occasions. It was explained to us that his wife was likely overcompensating in her care for him now, as she felt guilty for thinking that his extended periods of absence away from the family correlated to him having another wife. Although his brothers were not visiting during this time, his son and daughter were present, and significant time was spent explaining the dying process to the family and what physical changes should be expected. For the 48 hours prior to his death, he was symptomatically very settled and minimally conscious, with no changes to his infusion dose. On the morning of his death, he was peaceful, and we spoke with his wife to explain that we felt that death may occur later that day. She was calm, appropriately tearful, and accepting of this impression.

Several hours later that day, we were called to the ward urgently as the nursing staff felt that he was dying imminently. On our arrival, the patient exhibited agonal breathing, and there was significant disorder in the room. His wife was hitting his chest with both her fists and shouting at him; the brother-in-law was holding his legs, trying to pull the patient off the bed; and the daughter was on the floor screaming. The wife and daughter were screaming at us to send him to do cardiopulmonary resuscitation and send him to the intensive care unit. The patient's son, the main decision-maker for his father arrived, and together we managed to calm everyone down and ensure that they were at his side, praying, as he took his final breaths. Inevitably, once the death had been certified, there was more distress, with the daughter fainting and the brother-in-law hitting his head against the wall and subsequently being admitted to the emergency department with chest pain. Interestingly, throughout all this commotion, the patient's elderly mother was sitting quietly in the corner of the bedroom. A number of hours after her death, after all the members of the extended family had visited and gone, the wife then had a final outpouring of emotion when she screamed and proceeded to destroy the room, ripping the television (TV) off the wall, ripping the curtains down, and breaking all the furniture in the room to such an extent that the police had to be called.

DISCUSSION

While it is safe to say that we expected some distress from certain members of the family, the intensity of these events was still a surprise to everyone on our team. It did occur to us at the time that the patient's mother was extremely calm and collected despite the chaos around her. A few days later, during a discussion, it became apparent what had transpired in the last hours of our patient's life. Approximately an hour before he died, our patient apparently experienced a moment of terminal lucidity—he woke up, looked at his wife and mother, and said, "I'm very sorry to say this now, but you are right, I do have a second wife," before suddenly losing consciousness again.

To those of us working in palliative care, this unexpected return of consciousness or mental clarity just prior to death (terminal lucidity) is a well-recognized phenomenon.[2] This, however, was the first instance of the terminal lucidity event having such significance in our understanding of family dynamics. Our patient had kept his cancer diagnosis secret from his immediate family for a few years, and so the fact that his wife was initially angry and suspicious that he may have had another wife, then consumed by guilt for having had these thoughts in the first place, felt reasonable to all of us in the team. Certainly, a debriefing session was held with the team, during which they were encouraged to adopt a less critical perspective towards the wife's behavior on the ward. Numerous hours were dedicated to supporting the family, and although a significant expression of grief was anticipated at the moment of death, the physical nature of the wife's response nonetheless took everyone by surprise.

Not all family relationships are smooth and easy-going; inevitably, there will be some conflict. This is neither good nor bad; it simply is. The family of our patient was no different, and these were some of the specific family dynamics that we hypothesize are at play.

- The patient married his wife at the age of 15. This resulted in a degree of estrangement from his family, notably his brothers and, to a lesser extent, his mother. His wife had very little interaction with her husband's family.
- The patient's wife came from a very poor financial background, and her family was financially dependent on her. This could explain some of her distress at her husband's death.
- The wife's brother and his family were also financially dependent on the wife. This may go some way toward explaining why her brother was so distressed.
- The wife has had two years of significant emotional turmoil. All the time that her husband spent away from his family having medical treatment abroad, she interpreted this as time he was spending with a second wife. Imagine the emotional rollercoaster and guilt she must have felt while looking after him, then the last-minute revelation just before he dies.

When teaching communication skills, we say that patients and their relatives behave a particular way because of their lived experiences. We are usually not aware of everything that they have experienced during their journey with serious illness, nor are we always allowed to discuss these experiences with them. The earlier the palliative care team can engage with a patient and their family, the better the relationship and, therefore, the communication.[3] Engaging at a late stage, just prior to death, is fraught with difficulty[4] – we are 'parachuted into' a highly emotionally charged environment with few cues to help us navigate that family's dynamics. Being able to work effectively in this sort of environment requires a specific skill set—one that palliative care teams can offer.

CONCLUSION

While this narrative cannot be viewed as research, we felt that the case beautifully illustrated how family dynamics impact both a patient's end-of-life care and the team providing the care.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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