



# As hard as it was for us, it was harder for him

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Though patients living alone make up a small proportion of patients that we see in home hospice care, the challenges they face are multi-faceted and unique to them (1). In my modest experience as a medical social worker within a home hospice, working with this special group of clients has been professionally challenging, and personally difficult. I have witnessed first-hand the challenges they face: the physical pain, the emotional distress, and the practical difficulties of managing daily life while coping with a life-limiting illness, alone at home. Lacking caregivers, they are forced to rely on their own limited resources (2). Yet, I have also found them to be fiercely self-reliant and determined to maintain their independence, despite inconvenience and risks faced.

Such was the case with Mr. Dave. When our clinical team was asked to visit, he would often refuse to see us. Even when we were successful, he appeared cold and dismissive, making it known that our welcome was short. My memory of him during those first interactions was that of an angry man. Engaging him was a monumental task. He was described as abrasive, frequently raising his voice and making sarcastic comments. We settled for making periodic visits. Sometimes, he would even cancel a visit moments before we arrived, or would refuse to admit us when we were at his door-step.

In the process of physical deterioration close to end of his life, his mobility declined and his dependency escalated. When he found himself struggling with his daily routines

and needs, he began to seek assistance from neighbours and friends. This help was short-lived; they were unable to cope with the intensity and frequency of support needed. They began to avoid and distance themselves from Mr. Dave.

Our care team was constantly concerned and conflicted with the sub-optimal care Mr. Dave received. The team had experienced similar patients who had suffered falls and could not get up, stuck in their predicament for days, unable to call for help. The team was worried that Mr. Dave likewise could become incapacitated in his own home. With his limited social support, this could mean becoming trapped alone or even found dead after many days.

Alternative care arrangements were explored; we brought up the idea of going into an inpatient hospice; he declined. He refused all placements and was adamant about staying at home, claiming that he could handle everything himself. Our team felt tremendous frustration with the situation, outweighed only by our concern for his well-being and safety. Why did he insist to stay? Did he not see the risk he was taking and compromise to his well-being by not having his care needs met? The team wrestled with the ethical dilemma of his safety versus his autonomy. The risks were bearing on him and the team day after day. We debated when to report him to the adult protection service on the grounds of self-neglect, to extricate him from home and house him in temporary care.

During those deliberations, my mind wandered back to

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our early interactions with him. I began to ask myself how I would respond if I were in his situation; like him, I prize my independence. I gradually empathised with his frustrations and fears, facing challenges that he had no control over. It dawned on me that his ‘abrasiveness’ might have been a way to protect himself. I brought these thoughts to my interdisciplinary team. Through this exercise in curiosity, we were able to look past his anger and see the person that was Mr. Dave.

We visited him again, but this time we invited him to share why staying home was so important to him. We learned that he was a deeply spiritual man. His home was his sanctuary, and he protected it by binding spirits to various plants that lined his home. He also valued his family altar, where he would leave offerings for his deceased parents. In his words, it was “the least he could do for them now”. Staying at home was essential, especially for the upcoming ‘Hungry Ghost’ month, the period on the Chinese lunar calendar where the spirits of the deceased return to receive offerings.

With newfound understanding of Mr. Dave’s beliefs, we finally forged some rapport with him. He became more open. His tone towards us started to shift. He felt safe enough to share his fears and unfinished business. He expressed a need to release the spirits from the plants that protected his home; and wished for his family altar to be maintained by his siblings, so that his ancestors (and himself eventually) could continue receiving offerings and prayers.

During later visits, the topic of reconciling with his siblings was brought up. Mr. Dave hoped to look past differences and reconnect, given that his siblings were the only family he had left. There were difficulties engaging his siblings at first, but upon learning of Mr. Dave’s condition, they eventually reconciled and even ended up nursing him at home. Mr. Dave found meaning in being acknowledged and cared for by them. Less than a month later, he passed away peacefully in his own place, surrounded by his siblings.

Today, I recall Mr. Dave not as an angry man, but one who stuck to his values, and stayed courageous despite feeling afraid and alone. His emotions spilling out were signs of his troubles. His end-of-life journey was a culmination of the losses he had to face: his family, and friends, his independence, and even his identity. He grieved, and in his own way, it was a lonely journey. As hard as the work can be for us, it was harder for him.

I have learned (and re-learned) many important lessons from him. The importance of balancing our desire to

minimise risks versus respecting the patient’s autonomy and personhood. The importance of making decisions together with a patient, and appreciating the intrinsic value of remaining at home. It is easy to get caught up in the medical facts, but as palliative care professionals we must sit with our discomfort and not forget that patients are unique individuals. They have wishes that deserve due consideration in our bid to provide the best care possible.

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