PALLIATIVE CARE CASE OF THE MONTH

"Talking with patients and surrogate decision makers about Miracles"

by

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Case: ZS was a 33-year-old man who had recovered from COVID-19 in October of 2020. He presented two months later with migraines and dyspnea and was found to have decompensated heart failure with an ejection fraction of 10-15% and multiple LV thrombi. He was admitted for inotropic support with the plan for LVAD placement. Palliative care was consulted for support, assistance with symptoms and advance care planning. He was an active person who loved hiking and hunting and spending time with his family and friends. He was due to get married to his girlfriend of many years, which they had delayed given the pandemic. They wanted everyone to be together.

We followed him on the floor for a week. We made some medication suggestions and provided emotional support to him and his partner as they were coming to terms with this change. We had begun advanced care planning discussions with him and his mother who was his POA, given the plan for LVAD placement.

Z went for a right heart cath for pre-op workup, and based on findings it was decided he needed an Impella. Intra-operatively he was found to have a large LV thrombus and so an intra-aortic balloon pump was placed instead. After the procedure he was noted to have unequal pupils and was ultimately found to have CVAs involving multiple lobes which had progressed over the weekend. His prognosis was poor. We saw him on Monday and met with his mother, C, at his bedside. He was intubated and not responsive, even with trials of lifting sedation. C stated the whole family was shocked and devastated, but that their faith was giving them strength. C said that they were praying for a miracle.

Discussion: The word 'miracle' is derived from the latin word miraculum, which means a 'wonderful thing' or a 'marvel.' Miracles are referred to across most world religions. Over time the term miracle has come to mean many different things for many different people depending on faith and cultural background. Some of these meanings in a healthcare setting can include:

- A belief in a divine or supernatural intervention superseding the laws of nature
- Expression of denial or impending loss
- Expression of hope about possibility of recovery
- Expression of anger, frustration or disappointment over aspects of care. ([1,2])

A survey of the religious landscape in this country by the Pew research centre in 2014 showed that most people (89%) living in the United States believed in God and identify with a singular religion (77%). Almost 4 out of 5 people also believed that miracles occur. A majority of adults also regularly experience a sense of spiritual well-being and peace as well as a deep sense of wonder about the universe. ([3])

A survey of 2000 physicians in 2017 found higher rates of atheism and agnosticism compared to the general population. Physicians are also found to more often identify as spiritual, as opposed to religious, and less likely to use religion to cope with major life events. ([4,5])

Given these differing engagements with religion and spirituality, many providers may find discussions of miracles to be surprising and uncomfortable. Skepticism regarding miracles among medical professionals can lead to tension and distance in the therapeutic relationship. In deference to many people's belief in miraculous intervention, especially at the end of life, it is important for providers to be prepared to engage in discussions with patients and their families about miracles and how this influences decision making.([6])

Some strategies that can be employed are:

1.) Exploring miracles

Approaching the subject with curiosity and exploring what a miracle means to them can encourage open dialogue at the outset of the discussion and show respect for their beliefs. Most patients want their medical teams to explore their spiritual concerns. Exploring their religious or spiritual background can also provide context of where their belief in miracles stems. ([1])

> "You've mentioned a miracle. Can you tell me what a miracle would mean to you?"
> "Do you identify with a particular faith group or religion?"
> "Have you had experience with miracles yourself or with your family?"
> "What would a miracle look like given where we are right now?"

2.) Supporting hope while preparing for the worst

If the miracle is an expression of hope or optimism, it can be beneficial to support that hope and consider if there are other outcomes that can be hoped for. Framing the conversation as hoping for the best and preparing for the worst can allow for empathy and connection while also planning for a range of outcomes. ([1,7])

> " It sounds like hope is very important to you. Can you tell me more about what you are hoping for?"
> " It sounds like you are hoping for a miracle. I wonder are there other things you are hoping for too?"
> "I am hoping for the best, too, and at the same time I worry things may not go as we would hope them to. Can we talk about that?"
> " I talk about preparing for the worst with every patient I meet, not because we are giving up, but rather so that we can take care of them as best as possible, if things do not go as we hope"

Personal details in the case published have been altered to protect patient privacy.
For palliative care consultations please contact the Supportive and Palliative Care ***programs at PUH/MUH, 412-647-7243, pager # 8511, Shadyside, 412-647-7243, pager # 8513, Perioperative/ Trauma Pain, 412-647-7243, pager # 7246, UPCI Cancer Pain Service, pager 412-644-1724, Magee Women's Hospital, pager 412-647-7243 pager # 8510, VA Palliative Care Program, 412-688-6178, pager # 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore and Children's pager 412-456-1518***
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Discussion Continued

3.) Finding compromise and giving time

Often, the exploration and understanding of the family perspective can be effective in progressing conversations and redirecting focus for those hoping for healing intervention. If this does not occur, it does not mean the medical team should agree to medically inappropriate care. Boundaries need to be set while focusing on the patient's best interest. There is often a need for further conversations to find a middle ground. An example could be continuing current levels of care without escalating it, while aggressively managing comfort needs.

Giving time to the family is the most important thing as they come to terms with what their loved one is going through. There is not likely going to be a final decision or concrete outcome after one conversation. It is important to underscore non-abandonment and continued engagement with the family as they and the medical teamwork together for the best interest of the patient. Adopting a humble position and acknowledging the uncertainty of medicine can be a powerful bridge with patients and families, who may feel adrift or isolated. Pastoral care teams are an invaluable resource in these conversations and should be included.

Return to Case: We had many family meetings with Z’s family over the course of 10 days. His clinical condition continued to deteriorate. The family initially continued to ask for aggressive intervention and resuscitation. The ICU team shared that given his multiple strokes, he would not be a candidate for an LVAD or heart transplant, and he would need round-the-clock care going forward. The first compromise was not escalating care or performing CPR if his heart were to stop. After giving the family time and with further meetings, the family decided that when the balloon pump needed to be removed, they would allow Z’s body be the guide. The family stated they would hope for the miracle of his heart supporting itself; were it not to, they would agree to focus on comfort. After removing the balloon pump with no improvement in cardiac function, the family transitioned to CMO, and the patient died later that night.

References:

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7. Black AL, Arnold RM, Quill TE. Hope for the best, and prepare for the worst. Ann Intern Med. 2003 Mar 4;138(5):439-43