

Case 3: Small things for Marianna?*

For ten years Marianna has battled cancer. Her initial diagnosis was breast cancer. Six years ago she was diagnosed with multiple myeloma, a cancer of her blood plasma. This was treated aggressively but has now relapsed and the prognosis is that she will die within the next 6 months. She is currently an in-patient at your tertiary hospital. The cancer treatments have caused multiple morbidities, including extreme fatigue, brittle bones, and secondary oral infections. Yet, in her time outside of hospital and between treatments she has continued to paint, to assert her expressions of life, both beautiful and poignant. When she was able to in the years since her breast cancer diagnosis, she reveled in the many small things: the soft touch of her infant granddaughter's cheek and the delightful sounds of her family chatting all around her.

For many years prior to her illness Marianna set aside her own needs and interests to provide her ailing in-laws with the care they needed. Despite her devotion and attention to their needs they never acknowledged her care and concern. Marianna's primary regret during this time was not devoting sufficient energy and care to her only daughter Nadine who was, in Marianna's view, 'growing up on her own'. It has only been in the past few years, when Nadine married and became a mother, that they established a special bond. The linchpin of this connection was Marianna's granddaughter, Angela.

Yesterday, some of Marianna's family including Nadine and Angela gathered at her bedside on the unit to form a healing circle which involved the burning of sweet grass. Patients in nearby rooms and the care team on the unit noticed the smell of burning and smoke. Other patients and their visitors became alarmed as well as the care team who were especially concerned that the burning might start a fire in the room. They rushed into the room and sternly forbade Marianna and her visitors from performing the healing circle again. Marianna, trying to invoke humor in the moment joked: 'What are you going to do? Sue a dying woman for setting fire to some old weeds?!?'

The next day, Marianna pleaded to her care providers that the rituals performed by her family gave her much comfort and that it is one of the last small things she wants to experience before she dies.

Key Question

What should our approach be to supporting Marianna's dying wishes?

(Completed) Ethics Decision-Making Framework

1. Key Question:

What should our approach be to supporting Marianna's dying wishes?

2A. Facts:

- Marianna diagnosed with breast cancer 10 years ago
- Marianna has terminal multiple myeloma
- Marianna has other morbidities from treatments (fatigue, brittle bones, oral infections)
- M made time to enjoy the small things in life when outside hospital
- M enjoys presence of granddaughter
- M enjoys family presence
- Relationship with daughter Nadine is important to M
- M's family gathered for healing circle yesterday at bedside and burned sweet grass
- Burning caused concern for other patients/visitors and staff
- Care team forbade M and family from doing healing circle again
- M has asked care providers to allow ritual because it is important to her in context of her end of life

2B. Missing information we CAN find out:

- What are the details of the healing circle? Can it be done without actual flames/smoke? What is important about it to M?
- What is important to M at her end of life? Has anyone asked her/had conversations?
- What is important to her family/loved ones in end of life?
- What is actual risk of burning sweet grass?
- Is there a sacred space or other alternate space that family and M could use?
- Prognosis---will she go home?
- M may enjoy ritual (calming, positive for her)
- In house guidelines/policy for smoke?
- Is she in a single room or multiple bed?

2B. Missing information we CANNOT find out:

3. Values – it is important that...

- M is able to fulfill her comforts/wishes in her dying process/ living days
- We maximize M's Quality of Life as she defines it
- Patients and visitors feel safe/are safe in hospital
- As a health authority, we accommodate cultural, spiritual, religious rites/practices especially at the end of life
- We foster and support familial relations (people who will have to work with the grief of losing M)
- We minimize risks to M
- We minimize risks to other patients/their visitors

4. Possible Prioritization of Values:

5. Brainstorm options:

- A. Disallow M from having healing circle with threat of discharge (note: this is a provocative option to get your group thinking if they're slow on coming up with options 😊)
- B. Mitigate risk, e.g. have firefighter personnel present
- C. Find an alternate space outside of hospital building for healing circle
- D. Ask M if she would be more comfortable at her end of life in her own home with support from palliative care, and if so, support this move

6. Analyze options:

OPTIONS →

V		A	B	C	D
A	1	✓			
L	2	~			
U	3	~			
E	4	*			
S	5				

7. Make a decision:

The Ethical Decision-Making Process

1. Identify the key question
2. Identify the facts
 - a) What do we know for sure?
 - b) What don't we know that we can find out?
 - c) What information can't we know?
3. Identify guiding values – what matters?
4. Prioritize the values – what matters most?
5. Brainstorm the options
6. Analyze each option according to the prioritized values
7. Make a decision. Reflect and learn from it.

Find the complete ethical decision-making toolkit here:

http://fhpulse/clinical_resources/ethics_services/Pages/Default.aspx

Or contact Fraser Health Ethics Services at ethics.services@fraserhealth.ca

*SOURCE: Stewart, M. et al. (2014). *Patient-centered medicine: transforming the clinical method (Third Edition)*. Radcliffe Publishing. pages 54-55. No title in the original version. Adapted for FHES 2016 Conference by Allen Alvarez and Duncan Steele. Available at the FHES library at Central City Suite 400. Note: the book is CPD certified.