

Decision making in end-of-life management of ovarian cancer: *A case series*

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Introduction

Traditionally in Singapore, end-of-life care is seen as a family duty with ultimate decision making falling onto the eldest son. However, we have noted a shift in these roles. Understanding of these roles is critical for clinicians to help facilitate decision making, improve patient care and ensure effective communication with the family. Broadly, these principles can be transferred to populations where we see large numbers of South and East Asian communities such as the UK.

Objectives

This study seeks to explore the **patients’ preference in selection of the main caregiver**, who provides the majority of physical care to the patient, and the decision maker, who is tasked with deciding on treatment plans in case patient loses capacity .

Subjects

This qualitative study involved **9 ovarian cancer patients**. Subjects were Singaporean, over age 21 with ovarian cancer, undergoing active chemotherapy and could understand English.

Materials and methods

All 9 subjects viewed a video vignette about a mother and her three adult children following a diagnosis of metastatic terminal cancer. The doctor informs the family that chemotherapy could increase the mother’s life expectancy from 4 months to possibly 10 months. The doctor stressed that the chemotherapy was not curative.

Summary of topics suggested by children in the video:

Eldest son – advocates for chemotherapy as this would increase life expectancy

Daughter 1 – advocates to palliate their mother and prioritise comfort care as the family is struggling financially and she worries about the added medical expenses of chemotherapy.

Daughter 2 – advocates for palliation as she worries about the side-effects of chemotherapy for her mother and how this would impact her quality of life.

After watching the videos, the subjects were interviewed and asked their views on the video discussion, their thoughts on proxy decision making and their views on quality of life and chemotherapy and other disease modifying treatments in metastatic terminal cancer.

The transcripts of the audio interviews were deidentified and labelled with unique identifiers. 2 members of the investigating team coded the 9 completed transcripts. Grounded theory was used to identify key themes and code ideas during the analysis¹. Saturation was obtained after 8 cases. We were unable to recruit any further cases.

Important Cultural context

- Subjects were all Singaporean-Chinese.
- In Chinese culture, it is expected that children look after their parents into their old age.
- Traditionally, the eldest child is tasked with making health decisions for their elderly parents. In the context of end-of-life care, palliative care can often be seen as ‘giving up’ with children being blamed for making this decision.
- Medical costs are usually paid for fully or partially out of pocket with room for government subsidies depending on income bracket.

This will also give understanding of the role of family in healthcare decision making in the Asian immigrant population in the United Kingdom

Results

- Contrary to traditional beliefs of the importance of gender roles and familial duty, only 23% of patients prioritised their eldest son. 77% of patients (7 subjects) **prioritised willingness, capability, availability, and financial circumstances of family members** when determining their choice caregiver and surrogate decision maker. All subjects were Chinese.
- **All subjects** expressed that they would **opt for chemotherapy and disease modifying treatments**. This potentially could be at the cost of quality of life, Patients indicated that otherwise they would be giving up.
- 3 patients saw the daughters as being irresponsible and not filial for not advocating for treatment. **They felt they should at least try**.
- Several subjects brought up **anecdotal stories** of people they knew or had heard about who had successfully undergone chemotherapy and referenced this in their recommendation for the mother to undergo chemotherapy.
- Concerns were raised if the mother in the video could tolerate chemotherapy. **Palliation and comfort care were considered good options if quality of life was compromised after a course of chemotherapy**.
- The financial burden of treatment was of concern to the patients.

Discussion

- There is a shift away from traditional family roles to practical and sociocultural considerations. Caregiver willingness, capability and availability play a more significant role than the responsibility being placed on the eldest child.
- There is poor understanding of palliative care as an option. The patients feel that disease modifying therapy offers a chance at cure even when told otherwise.
- Culturally Confucian principles and stoicism prevail in the predominantly Chinese community in Singapore. As such, accepting chemotherapy and its associated discomfort maybe viewed as duty so as not to appear as ‘giving up’.
- It is noted that these 9 subjects were recently diagnosed and so it is possible that they may have different views if they were later in their cancer journey.
- Financial considerations were important as patients did not want to be a burden on the family.
- Patients tended to prioritise anecdotal evidences of friends or family who have undergone cancer treatment when making their decision rather than evidence presented by a healthcare professional.

References

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