



Appendix 1

**This appendix was part of the submitted manuscript and has been peer reviewed.
It is posted as supplied by the authors.**

Appendix to: White B, Willmott L, Close E, et al. What does “futility” mean? An empirical study of doctors’ perceptions. *Med J Aust* 2016; 204: 318.e1-3.18e5. doi: 10.5694/mja15.01103.

What does “futility” mean? An empirical study of doctors’ perceptions

Appendix 1: Interview Guide

Note: these questions are to be used as a flexible guide. The interviewer will begin with a general question like those described, and use the other questions as prompts depending on what the participant says. The interview will be conversational, and participants will answer questions in their own words and address issues in the order they wish.

General questions

Initial question: Can you please describe a situation from your experience (one you were responsible for or one from a colleague) when a person got treatment at the end of life you didn’t think they should have had?

- Why was this treatment provided?
- How did you feel about this experience?
- What do you think could have been done differently (if anything)?

What about a situation where a patient *didn’t* get treatment that you thought they should have had?

Can you describe a situation where treatment at the end of life was appropriately withdrawn?

Describe a situation where a decision was made to withhold or withdraw treatment that resulted in a poor outcome?

Have **you** ever given treatment you knew was futile (ie likely to be ineffective)? Why?

- What factors led to the decision?
- Why was treatment withheld/withdrawn?
- Why did you think that others/self thought treatment was futile/inappropriate?
- Why do you think that others/self thought treatment was appropriate?
- How did you feel?
- What was your colleague’s reaction?
- What do you think could have been done differently (if anything?)

Prompts

- ☐ Family
 - a. What role, if any, do you think family members play in the provision of futile treatment?
 - b. What role, if any, do you think patients play in the provision of futile treatment?
 - c. How often is futile treatment given just because family requests it?
- ☐ Interpersonal dynamics/communication
 - a. Some believe that communication plays a role in futile treatment. What do you think about this? (i.e. communication with other staff, family, patient)
 - b. Some believe that expectations play a role in futile treatment. What do you think about this? (i.e. expectations of other staff, family, patient, self)
- ☐ Institutional culture
 - a. Why do doctors make varying decisions about when to withhold or withdraw treatment at the end of life?
 - b. Is your practice similar to others in your specialty? Why or why not?
 - c. Interaction/opinions of nurses, registrars, other staff
 - d. Some say that this treatment is provided because doctors don't have enough time to have adequate conversations because of workload. What do you think about this?
- ☐ Training
 - a. What training (if any) did you receive in relation to how to deal with end of life care? Deciding when to cease active treatment?
 - b. Nature, duration, place of training
 - c. What, if anything, should be done to change this training?
- ☐ Resources (look for cues from participant)
 - a. Some say resources are a factor in assessing whether or not to offer treatment that may be futile. What do you think about this?
 - b. Some say that by providing treatment that is futile (even when there is some justification) others miss out on beneficial treatment. What do you think about this?
- ☐ Law
 - a. Some believe that if they do not provide treatment when a patient/substitute decision maker requests it, there may be legal consequences. What do you think about this?
 - b. What does the law say on this?
 - c. What do you think of the law? Is treatment provided because of it?
 - d. Have you ever had a situation escalate to a legal proceeding?
 - e. Thoughts on the legal proceeding?

- f. Does the law support your decisions in this area?
- g. Would an increased understanding of the law assist?
- ☐ Policy
 - a. Are there any policies/practices in your department/hospital/QHealth that deal with futile treatment at the end of life?
 - b. What do they say?
 - c. What do you think of these?
 - d. Do you use them in practice?
 - e. What about professional/ethics guidelines? Do they address this? What do you think of them?
- ☐ Nature of futile treatment
 - a. Think of instances in other specialties when this occurs? Which ones?
 - b. What is the nature of futile treatment provided?
(Resuscitation/medication/procedures, etc)?
 - c. What about your own specialty (discipline, department) – any examples?
 - d. How frequently do you perceive futile treatment occurs in your department?
 - e. Main reason that futile treatment is provided?
- ☐ Definition
 - a. What do you mean by futile treatment?
 - b. Can you define futile treatment?
- ☐ Improvement
 - a. Is it a problem? What troubles you the most about it? (harm to patient, resource use, doctor's autonomy, etc)
 - b. What do you think needs to happen (if anything) to address the issue of futile treatment?

Case example

- John is an 84 year old male with advanced dementia and end stage bowel cancer which has metastasised
- He is admitted from the high care unit of an residential aged care facility to hospital with abdominal pain
- It is possible to undertake surgery, but this is expected to have limited, if any, benefit
- John's daughter demands the operation despite the poor prognosis

What to do (listen for cues from participant):

1. Administer treatment? When? Why this point?
2. What information would you want?
3. How would you make this decision? Who would you speak to?
4. Any laws/policies/processes affecting your decision?
5. Cost considerations?
6. What if John did not have dementia and himself was requesting futile treatment?

Categorise

- Continue even if know is futile?
- Or stop because know is futile?