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Appendix 2

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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 2: Quotes from participants on key issues

Futility is about patient benefit

Quote A: “Treatment that's not going to improve a patient's longevity or quality of life essentially. … If you can't provide either of those, and/or is going to prolong some potential suffering, and there is a very low likelihood of being able to reverse that problem … then as I said, I don't think you should provide it just for the sake of providing it… you've got to provide treatment that's actually going to have some benefit, and if you can't achieve that, then what are you doing it for?” (Cardiology consultant, male)

Quote B: “Treatment that's unlikely to benefit the patient, basically. … Either in length of life, quality of life or any of the things that would be important to the patient.” (Oncology consultant, male)

Quote C: “… there is no measurable or meaningful benefit to that patient to have received or receive that treatment. … In improved quality of life, function, physical functioning and improved health in the broad sense.” (Palliative Medicine consultant, female)

Quote D: “Treatment that's not going to improve quality of life, improve symptoms or increase life expectancy.” (Respiratory Medicine consultant, female)

Quote E: “To me the quality of life is also a big factor. So if it's going to be three miserable months then I probably wouldn't do it, but if it's going to be three really good months and they were young and keen and wanted something done, I think they're all factors basically.” (Oncology consultant, female)

Quote F: “Or another way I might say sometimes is the burdens of this treatment far outweigh any benefits and it is not in your loved one's best interest from a medical point of view to do it. So usually it'll be about portraying, usually it's – so what I see is futile is where the burdens of the treatment outweigh, quite severely or significantly, any potential benefit.” (Pallative Medicine consultant, male)

Role of resources in futility

Quote G: “It's a quality of life [assessment] but I guess what I'm really referring to is, to be honest, is the extent of the resources you're actually going to use to get a certain outcome.” (Emergency Medicine consultant, female)

Quote H: “Then I guess as a distant third [factor,] there is the community, the hospital, the - that bigger picture thing. Is this a waste of money, a waste of resources? If we do this are we not going to be able to do something else;

those sort of things do factor in a little bit." (Renal Medicine consultant, female)

Quote I: "… it's often treatment with a high resource cost but also high impact to the patient. So for lower resource impacts and lower impact to the patient, it matters much less. To operate, to not operate is important. To put up some IV fluids versus not is a much lower level decision to make, in other words, because the impact is not as great." (Emergency Medicine consultant, male)

Assessing likelihood of patient benefit

Quote J: "Nothing in medicine is all or nothing. We're used to this idea of uncertainty all the time… There's only such a small number of things that would fit into 100 per cent beneficial or 100 per cent futile." (Renal Medicine consultant, female)

Quote K: "But mostly you have to in medicine go with the odds. If the odds are very much swayed in the fact that this isn't going to help the person, this person is going to die almost no matter what I do, then you've got to expect that that's what is going to happen. It's wrong to try and build false hope in people when really there is very little false hope there." (Geriatric Medicine consultant, male)

Quote L: "… no chance or virtually no chance of a positive outcome or an improvement in the patient's condition with the proposed treatment. … You'd have to be pretty confident to use that word futile. I've rarely written that on the chart. I actually don't write that word." (Respiratory Medicine consultant, male)

Quote M: "… no chance of survival as being futile or no chance of a meaningful recovery." (Neurosurgery consultant, female)

Quote N: "… no chance of an outcome, that the patient would think was reasonable." (Neurosurgery consultant, female)

Difficulties in defining futility

Quote O: "It's very hard to define futility, as I said, in a way that gives you an all encompassing definition that can be just easily applied to all of the situations. It is just trying to weigh up the pros and the cons and when the cons far outweigh the pros then it's futile. But what the people involved consider are the pros and the cons and the strength of each - what weight is put on the different pros and cons is different. That's where the one definition fits all doesn't fit very well." (Renal Medicine consultant, female)

Quote P: "That's really tough. Futile treatment is providing ongoing treatment or life sustaining measures in a situation where the prospect of survival for any reasonable period of time, or survival with an appropriate, or with a reasonable quality of life, yes, where the prospect of that is remote. The trouble is, it's very hard, what's remote? What's a reasonable quality of life? What's a reasonable prospect of survival? Those things, and it's those grey

zones that make it really difficult… What I would view as futile would be different to other doctors, would be different to patients." (Renal Medicine consultant, male)

More objectivity is possible in futility

Quote Q: "... a lot of people think futility decisions are subjective. That's ignorance. It's not. There is - although it's not fool proof, one hundred per cent objective, there is some objectivity coming into the discussion from all the literature that comes around from the world. You need … to try and keep yourself abreast of what's happening in the literature. Understand different patient groups, who are likely to do well, who are not likely to do well, so understanding of current literature and what's happening and what others have done, learn from others' mistakes." (ICU consultant, male)

Justifiable futile treatment

Quote R: "Sometimes just giving them a few days, so it can actually sink in. While treating them isn't going to get them out of hospital or isn't even going to keep them alive, they're going to die anyway. Having a little bit of time to (1) for them to accept it, (2) for family to accept it and to come to terms with that, is often useful. That's probably to be honest more often where I think more futile treatment - what could be classed as futile treatment, happens. I wouldn't [call that futile], but some people would. You can argue it is because someone still dies, but I think there are things that you gain from it." (Respiratory Medicine consultant, male)

Quote S: "It's difficult, isn't it? I suppose, futile treatment - what may be medically futile, in terms of the medical outcome, may still be beneficial from the point of view of giving the family and/or the patient time to adjust to the fact that their illness is terminal. So, that's not really futile from that point of view. From a practical point of view, I guess, that time frame usually tends to be fairly limited, anyway. It's usually of the order of weeks to months before something serious happens. It would be very unusual for someone like that to go on having years of treatment. So… …it's a short term issue, usually." (Renal Medicine consultant, male)