Research Results

Can community dwelling older adults complete a person based Advance Care Directive to provide useful information to substitute decision makers?

Purpose

The purpose of this research was to compare two Advance Care Directives (ACDs) to find out whether:

- Adults over 65 can complete an ACD independently
- Family members find the information in the ACD helpful for substitute decision making
- Doctors find the information in the ACD helpful for “best interests” decision making

Participants

60 consumers were recruited to the study and identified a Substitute Decision Maker (SDM) to participate with them. Consumers completed either the Statement of Choices (SOC) or the Alfred Health Advance Care Directive (AH ACD).

Both ACDs included values based questions (eg. ‘things I value’, ‘a good death’, ‘lifestyle preferences’) and also medical based questions (eg. ‘life prolonging treatments’, ‘unwanted treatments’)

13 Alfred Health doctors were recruited to the study.

What was involved?

Consumers and SDMs

- Consumers independently completed ACD
- Consumer & SDM attended scenario testing (3 medical scenarios)
- Consumer & SDM provided feedback
- Consumer & SDM reviewed scenario results & discussed with a clinician
- Some consumers chose to complete another ACD post scenario testing

Doctors

- Doctors were sent ACDs
- Doctors used ACD to select treatment option they would provide for consumer in 3 scenarios
- Doctors provided feedback

Results

1. Agreement in decision making with given scenarios.

- Overall agreement in decision making declined as the scenario became more uncertain for both consumer and SDMs (88% to 42%) and consumer and doctors (90% to 48%).
- There was minimal difference when comparing the two directive types.
2. Consumer, SDM and Doctor feedback.
- Majority of users reported the directives were easy to understand, logical and with sufficient space to write answers, regardless of directive type.
- Majority (93%) of consumers felt they could complete the directive independently.
- Majority of SDMs (90%) felt the directives were helpful with the decision making process.
- Doctors expressed a small preference for the AH ACD however the majority (92%) reported that either directive type would assist in making treatment decisions.

3. Consistency between directive completed pre and post scenario testing
- Following the scenario testing, the majority of consumers made changes to their directive.
- Responses were more consistent for values based questions compared to questions relating to medical treatments.
- New concepts and treatment ideas were included in the post scenario testing version for many consumers.

Discussion
The results from this study indicate that whilst community dwelling seniors can independently complete both the AH ACD and the SOC there remains a number of variables that contribute to the usefulness of these documents for substitute decision making. The difficulties around substitute decision making are most evident in complex and uncertain medical scenarios. Directives alone can guide decision making however they aren’t always enough in complex medical scenarios to ensure that an individual's choices are respected. Individuals should be encouraged to have conversations with families and loved ones about their values and preferences for quality of life and supported by clinicians to have discussions around preferences for medical treatment. Both these discussions should be documented on a directive however the type of this directive is less relevant than the discussions.

Key Learning's
- The writing down of wishes is only one step in the advance care planning process. The conversation about these wishes is a fundamental part of the process.
- Individuals should be encouraged to have conversations with families and loved ones about their values and preferences for quality of life and supported by clinicians to have discussions around preferences for medical treatment.
- The use of scenarios can be effective in assisting consumers to have these conversations.
- These conversations should be documented on a directive however the type of directive is less relevant than the discussions.