What are the views of older people on advance care statements and their role in end of life care and treatment decisions?

**Design**
Qualitative study.

**Setting**
Sheffield, UK.

**Participants**
32 older people (72% women; 27 were 60–80 years of age) who were recruited from 6 diverse community groups representing older people in Sheffield, UK.

**Methods**
8 focus group discussions were held with participants to explore beliefs and understandings, risks and benefits, and preferences of older people regarding “life prolonging” and “basic care” technologies in end of life management. A slide show describing a man with early Alzheimer’s disease and his plans for end of life care was used to prompt discussion. The discussions were transcribed verbatim and analysed for major themes.

**Main Findings**
Advance statements can aid personal integrity and help families of older people. Although advance care statements were a new idea to most participants, they identified several positive attributes of such statements. Participants recognised that advance care statements have the potential to enhance choice and autonomy about issues of care and treatment before onset of cognitive impairment. A slide show describing a man with early Alzheimer’s disease and his plans for end of life care was used to prompt discussion. The discussions were transcribed verbatim and analysed for major themes.

**Main Findings**

5 themes described the views of older people on advance care statements and their role in end of life care and treatment decisions.

- **Concerns about future applicability of advance care statements.** Some participants expressed concern that completing an advance statement might be interpreted as a request for euthanasia. The term “pulling the plug” was used to describe the type of clinical actions they thought would result from adherence to an advance care statement. Such concerns and doubts about the meaning of euthanasia and how it differed from adherence to an advance care statement. Several participants also stated that advance statements would be a good way to avoid extra stress during serious illness because important decisions about care and treatment that may be urgently needed will have already been considered and agreed upon. Advance statements were also reported to have the potential to relieve families of the “burden” of decision making.

- **Advance statements and euthanasia.** Some participants expressed concern that completing an advance statement might be interpreted as a request for euthanasia. The term “pulling the plug” was used to describe the type of clinical actions they thought would result from adherence to an advance care statement. Such concerns and doubts about the meaning of euthanasia and how it differed from permissible forms of non-treatment were identified in relation to all types of care and treatment innovation addressed in the focus groups.

- **Concerns about future applicability of advance care statements.** Most participants envisaged problems in making decisions for a future old age. Participants recognised difficulties associated with anticipating their requirements during a final illness and getting the timing of advanced care planning right. Participants perceived a risk of leaving it “too late.”

- **Worries and difficulties in thinking about and discussing death and dying.** Although some participants indicated that they had thought about their own dying and death at length, for others found that dying was not easy to contemplate. Most participants thought that family members would be able to refuse or give consent for particular types of treatment on their behalf. As a result, some did not feel the need to think about making an advance statement. However, participants also spoke of difficulties in discussing end of life care with their families.

- **The need to build trusting relationships with clinicians.** Initially, advance care statements were viewed by some participants as a safeguard against physicians “playing God.” However, some recognised that in certain situations (eg, sudden illness), physicians needed to make decisions on their behalf, often “snap” decisions without time to consult family or previous statements of wishes. This recognition was linked to an awareness that when dying, a person may no longer wish to adhere to the stipulations of an advance statement. Participants recognised the paradox of wanting control and autonomy but also wanting to be cared for at a time of vulnerability.

**Conclusion**
Older people perceived that advance care statements have the potential to aid personal integrity and help their families during terminal care and treatment decisions, but they also identified several barriers to their completion.

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**Commentary**

Between 1980 and the early 1990s many studies about end of life issues and advance directives were published in Canada and the US. Most concluded that patients were the best decision makers about their own care. However, patients and their families needed education to understand the complexities of their diseases and the available options for care. If written, directives should be reviewed yearly and changed if thinking changes. In Canada and the US, advance directives are only used if patients are identified as incompetent.

The study by Seymour et al contributes to this body of knowledge from a UK perspective and provides new understandings of the perspectives of older people about advance care statements. A study limitation was that participants received minimal education about types of directives, legalities, and ethics. The presentation did not seem to include other aggressive life sustaining options such as intravenous blood transfusions and surgery, but instead focused on terminal sedation, cardiopulmonary resuscitation, and tube feeding. This information is minimal compared with options offered in acute care today. Also, most participants were >80 years of age and healthy and thus might have had problems defining their advanced directives because of the need for abstract thinking.

Advance directives are a valid way of identifying the wishes of competent patients who enter the healthcare system. Nurses are in a good position to discuss care options with patients during routine care episodes and can educate them about available options. As professionals, we still do not obtain elderly patients’ preferences for care as often as we should. Therefore, nurses, physicians, and other healthcare providers should develop care plans that reflect patient and family goals and wishes for treatment. This can only be achieved by improving communication with patients and their substitute decision makers.

Judith A Lever, RN, MSc(A), GNCC
Hamilton Health Sciences, Henderson Site
Hamilton, Ontario, Canada

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