

Recognition and expressed insight on Advance Directives by patients with cancer

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Abstract

Aims

Advance Care Directives have recently achieved legal recognition in Ireland. Our study sought to determine awareness of and attitudes towards Advance Directives in a cohort of Oncology patients.

Methods

A short survey was completed by inpatients on an Oncology ward over a four week period. Patients were excluded in cases of cognitive impairment, short prognosis and severe anxiety.

Results

30 inpatients completed the survey, out of 125 total inpatients during the study period. No patient included had an Advance Directive or were aware of the legislation; 17% (n=5 patients) were aware of their existence. 87% (n=26) of patients stated they would consider making an ACD.

Discussion

Awareness of Advance Directives among this cohort of oncology patients is low, however most patients are willing to engage in a discussion about their treatment preferences.

Introduction

Advance Care planning is a process by which patients with life-limiting illnesses can document their preferences for end of life care. This process often results in lower utilisation of futile, life-sustaining treatment, and increased use of palliative care¹. Advance Care planning can also help to alleviate stress and anxiety in family members of critically ill patients².

In April 2023, Ireland enacted the Assisted Decision Making and Capacity Act (2015)³ – which gives legal protection to Advance Care Directives (ACDs), and allows patients to nominate a decision making representative. In the majority of Western European countries, Advance Directives have legal standing – including the UK, Spain, France and Germany⁴. In Ireland, the “Think Ahead”⁵ pack has been developed as a means to guide patients through the process. An Irish study has found this tool is acceptable in 83% of a sample of patients in the community, whereas 17% found it upsetting⁶; potential for patient distress is one of the main barriers to initiating an Advance Care discussion. Physician factors such as lack of formal training and fear of upsetting the patient can also limit discussions⁷. However, if left until a late stage, patients may be too ill to express their wishes for end of life care⁸. With this in mind, our study sought to assess opinions towards Advance Directives, in a cohort of Oncology patients.

Methods

All inpatients under the Medical Oncology service, with capacity to discuss this topic, were considered for inclusion. Reasons for exclusion included cognitive issues, limited life expectancy (<60 days), and those in whom it was felt that completing the survey would cause distress, due to underlying anxiety. Completion of a questionnaire was facilitated by a doctor known to the patient, to help explain the components. In the case of patients becoming distressed while completing the survey, the questionnaire was terminated and the patient was excluded. The study was run over a four week period in April 2023. Given that this is a service evaluation study, ethical approval was deemed unnecessary by the Hospital Ethics Committee.

Results

A total of 30 patients were surveyed, out of 125 inpatients during the survey period. Most common reasons for exclusion were cognitive issues (n=30), short prognosis (n=18) and anxiety (n=12). Two patients became distressed while completing the survey and were excluded. No patient included in the study had a formal Advance directive; 17% (n=5

patients) were aware of their existence. No patients were aware of the new Irish legislation. 87% (n=26) stated that they would consider making an ACD. 77% (n=23) felt that an ACD should be made when one is well, whereas 16% (n=5) believe it should be drafted when one is unable to look after oneself or becomes dependent on others. Regarding healthcare decisions, 30% (n=9) would allow their treating Oncologist to fully guide their decisions (refusal of ICU, etc.) whereas 70% (n=21) would make their own decisions with input from their consultant. 57% (n=17) would like ACD preferences documented in their medical notes, while 36% (n=11) feel it is more appropriate to carry it on their person. When asked who they would elect as their healthcare representative, 40% chose their partner and 43% choose their child. 80% of patients believe that their family are aware of their medical wishes.

Figure 1: Survey

BACKGROUND INFORMATION

Diagnosis and Stage	
Current and prior treatments	
Co-Morbidities	

AWARENESS OF ADVANCE CARE PLANNING

Do you know what ACD is?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Aware of Assisted Decision Making Act	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Do you have an ACD?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If yes – reasons for having an ACD		
If no – would you consider making one		

WHEN TO CREATE AN ACD (under what circumstances should you create them - tick)

1) When well	
2) If unable to look after yourself	
3) If dependent on others	
4) If unable to live at home	

SPECIFIC DECISION MAKING (With guidance or alone - tick)

1) Fully guided by treating oncologist	<input type="checkbox"/>
2) OR guided but Oncologist but would refuse certain treatments	<input type="checkbox"/>

HEALTHCARE REPRESENTATIVE

Who would you pick to be representative	1) Partner <input type="checkbox"/> 2) Child <input type="checkbox"/> 3) Sibling <input type="checkbox"/> 4) Parent <input type="checkbox"/> 5) Friend <input type="checkbox"/> 6) Other <input type="checkbox"/>
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How would you make people aware?	1) Have it on your person? 2) Highlighted in medical records 3) Medical app e.g. my patient record
Currently – is anyone aware of your wishes?	Yes <input type="checkbox"/> No <input type="checkbox"/>

Discussion

Our study shows that while awareness of ACDs is low in our patient cohort, most patients are willing to engage in a discussion about their wishes, and feel that this should be done while they are still in relatively good health. The high number of patients excluded due to cognitive issues or acute illness suggests that clinicians are perhaps leaving it too late to initiate this discussion. Notably, 30% of patients would allow their treating Oncologist to guide all their healthcare decisions – this highlights the trust that patients have in their doctor, and emphasises the importance of early and frank discussion regarding expectations and goals of care. Moreover, the development of a national guideline or specific training for physicians in this area would be highly valuable.

Limitations of this study include the small patient number, and the fact that it was completed less than a month after the commencement of the new legislation (hence awareness of ACDs within the general public may increase with time). We plan to disseminate these results to all within the department to prompt early consideration of Advance Care planning.

Declarations of Conflict of Interest:

None declared.

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