

## Newcastle Cancer Control Collaborative (New-3C), NSW

### Haematological cancer patients' perceptions of advance care planning

#### *Background*

Advance care planning (ACP) describes the process of discussing or documenting preferences for future medical care. ACP supports doctors and family members to make decisions that are respectful of patients' preferences in situations where patients no longer have capacity to make or communicate their wishes. ACP may improve patient satisfaction with care and reduce stress, anxiety and depression. Assessment of perceptions of ACP among people diagnosed with haematological cancer will inform approaches for improving communication about end of life care for haematological cancer patients, families and clinicians.

#### *Aims*

To investigate haematological cancer patients' perceptions of communication about end of life care, including:

- willingness to answer survey questions about ACP
- preferences for timing of ACP discussions
- self-reported completion of ACP elements.

#### *Method*

Longitudinal survey study of adult haematological cancer patients. Eligible patients (attending second follow-up appointment after receiving diagnosis; life expectancy of  $\geq 12$  months) are provided with a study pack by their haematologist. Study surveys 1 and 2 are mailed or e-mailed to consenting patients at 1- and 12-months post-recruitment, respectively.

#### *Preliminary results (survey 1)*

To date, survey 1 has been completed by 48 participants (intended  $n = 90$ ; consent rate = 26%; response rate = 89%). Mean participant age is 67.8 years ( $SD=11.0$ ). The majority are males (58%), have completed high school or higher education (96%) and were born in Australia (73%). Ninety-four per cent ( $n=45$ ) were willing to answer questions about ACP. Forty-four per cent (95% CI: 0.29, 0.60) indicated that they would prefer to begin ACP discussions with their haematologist when diagnosed. The proportion reporting ACP completion was: advance directive (7%); appointment of enduring guardian (27%); discussed preferences for life-prolonging treatments with haematologist (14%) or partner/family (27%); discussed preferences for location of end of life care with doctor (2%) or partner/family (14%).

#### *Conclusion*

Despite the potentially confronting nature of ACP discussions for haematological cancer patients, their families and doctors, a substantial minority of haematological cancer patients appear to value having early conversations about preferences and expectations for medical care. Changes in patients' preferences between the 1 and 12 month surveys will be assessed once data becomes available. Low study consent rates present a potential limitation for the generalisability of the findings.

#### *Dissemination*

This was one of several studies presented by New-3C at the 13<sup>th</sup> Behavioural Research in Cancer Control Conference, 3-5 May, Melbourne. Other New-3C presentations included:

- Do people with cancer and their support persons agree on end of life issues?
- Who decides and at what cost? End of life preferences of medical oncology outpatients
- Barriers to the provision of optimal care to patients dying in hospitals: perceptions of nurses
- A discrete choice experiment to assess cancer patients' preferences for when and how to make treatment decisions
- What models of peer support are most appealing to cancer patients? A cross-sectional survey
- A consumer action model to improve delivery of patient centred care: Challenges and successes.