**Real world management of multiple myeloma: Initial results from the Australia and New Zealand Myeloma and Related Diseases Registry**

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**Background**

Multiple myeloma (MM) accounts for a high community burden of disease, with 1500 new cases diagnosed in Australia annually. The Australia and New Zealand Myeloma and Related Diseases Registry was established in 2012 to explore the epidemiology, variation in practice and clinical outcomes for patients with MM. The registry captures information on patients with MGUS also (27% of participants) and quality of life is assessed to enable health economic analyses. The registry has a multidisciplinary steering committee and is steadily expanding to new sites.

**Methods**

All patients registered from 21 January 2013 to 13 September 2015 were included in the analysis. Patient baseline characteristics, diagnosis, therapy and outcomes were assessed. Time to disease progression was estimated using survival analysis and logistic regression was used to model associations with partial response or better to therapy (≥PR).

**Results**

In total, 692 patients were registered (59% male), of whom 469 (68%) had a diagnosis of MM. Mean age at diagnosis was 66 years (range 22-98) with 33% of MM patients over 70 years of age.

Common symptoms (CRAB mnemonic) were identified in 67% (316/469) of MM patients: 32 (7%) had elevated Calcium, 41 (9%) had Renal failure, 117 (25%) had Anaemia, and 248 (53%) had Bone lesions.

ECOG performance status was available for 284 MM patients: 35% were fully active, 42% were unable to do light work, 15% were self-caring but unable to work, and 8% were very limited in their activities.

First-line chemotherapy data were available for 385 patients: 324 (84%) received bortezomib-based therapy with 47 (12%) receiving an immunomodulatory drug; 3 received both. At least 43 patients had received second line chemotherapy. Of 380 patients with review data, 32 had died (median follow-up time: 16 months). Response data were available for 266 MM patients; overall response rate (≥PR) was 82%. An autologous stem cell transplant (ASCT) had been performed in 162 MM patients (35%). In 27% of 157 cases where ASCT was not planned, the rationale was age. Comorbidities and performance status also influenced the decision to perform an ASCT in 12% and 9% of cases respectively.

**The Myeloma 1000 Project**

This is a biobank substudy of the registry. A one-off blood collection involving formal consent will be taken from 1000 patients with MM and 1000 patients with MGUS who are newly diagnosed, are participants in the registry and have received no treatment. Participating sites are not required to process bloods or collect extra data.

**Conclusion**

‘Real world’ myeloma data are scarce internationally and in Australia and New Zealand. Most patients are treated with bortezomib-based induction therapy. Maturing registry data will describe epidemiology, treatment, and outcomes and help inform future clinical management and research.

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Contact us

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This biobank substudy will allow assessment of biomarkers that predict treatment response, patients at risk of developing myeloma, and patients at risk of accelerated disease progression. Preliminary findings are promising.

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