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652.Multiple Myeloma: Clinical and Epidemiological

The Impact of Continuous Lenalidomide Maintenance Treatment on People Living with Multiple Myeloma - a Single-Centre Qualitative Service Evaluation

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Background: Randomised trials examining continuous lenalidomide maintenance after autologous stem cell transplantation (ASCT) in patients with multiple myeloma (MM) have demonstrated progression free survival (PFS) and overall survival benefit compared to placebo. In 2021 the UK National Institute of Clinical Excellence (NICE) approved lenalidomide maintenance for all newly diagnosed National Health Service (NHS) patients receiving ASCT after induction chemotherapy. Patient-reported outcomes from observational studies suggest lenalidomide causes tolerable adverse effects. However, clinical trial data demonstrate that neutropenia, fatigue, neuropathy, and gastrointestinal issues are common, particularly in the first six months of treatment, and that lenalidomide increases the risk of secondary malignancies.

Before lenalidomide maintenance was used in this setting, individuals would typically enter a treatment-free phase after ASCT, where they might experience a reasonable quality of life (QoL) without treatment burden. Studies suggest that medication breaks allow patients to detach from the 'illness' experience, but with continuous lenalidomide that opportunity is lost. Whilst the PFS benefit of lenalidomide maintenance is proven, both short- and longer-term toxicities reported in clinical trials suggest the trade-off between efficacy and harm should be considered. In-depth information about how continuous lenalidomide impacts individuals' QoL is scant. The overall objective of this qualitative service evaluation was to examine patients' experience of lenalidomide maintenance, including perceived impact on QoL and experience of side-effects. It was anticipated that findings would result in clinical service improvement through the delivery of communication better suited to patients' needs and priorities when facing treatment choices.

Methods: We conducted 20 one-to-one semi-structured interviews with purposively selected patients (10 female and 10 male) from a specialist MM center in London. All participants had undergone induction chemotherapy followed by ASCT and were receiving continuous lenalidomide. Ages ranged from 45 to 71 years (median 58). The sample comprised 12 White British, 2 Black Caribbean, 1 Black African, 1 Asian Indian, 2 from other ethnic groups and 2 with undisclosed ethnicity. Lenalidomide treatment duration varied; seven patients had received lenalidomide for 1-6 months, five for 7-12 months, five for 13-18 months, one for 19-24 months, and two for over 24 months. Reflexive thematic analysis was used for data analysis.

Results: Four themes were developed from the data: 1) Lenalidomide: understanding its role and rationale, 2) Reframing the loss of a treatment-free period to a return to normal life, 3) The reality of being on continuous lenalidomide maintenance: balancing hopes with hurdles, 4) Gratitude and Grievances: Exploring patients' mixed perceptions of care and communication. Most patients believed lenalidomide maintenance would double remission time and were compelled by the relative certainty it offered, which contrasted with the unpredictability of MM. Many participants reported that lenalidomide helped to diminish fears about relapse, and thus most did not feel they were missing out on a treatment break. The impact of lenalidomide maintenance on patients' QoL varied; younger patients reported no/negligible side-effects, while several older patients with comorbidities described significant symptom burden, such as skin rashes, debilitating fatigue, unpredictable gastric disturbances and bone pain, occasionally leading to treatment discontinuation which caused distress at the perceived loss of

prolonged remission. The transition from frontline to maintenance treatment required a return to greater patient autonomy as medical support was reduced. Some patients described anxiety and depression in this period, suggesting the need for greater support. The study also highlighted specific challenges that younger patients experience, such as concerns about sexual transmission and fertility, which merits further research.

Conclusions: Understanding the real-world symptom burden in MM is key as continuous treatment becomes routine. Qualitative research on the impact of treatment could lead to a more comprehensive understanding, helping patients cope with the increasingly chronic nature of this disease.

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