Proposed standard of care for active monitoring in Waldenström macroglobulinemia from a UK-wide patient-expert collaboration

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ABSTRACT

Introduction: Patients with Waldenström macroglobulinemia (WM) are often asymptomatic at diagnosis and may remain so for several years. Regular monitoring for clinical changes, known as active monitoring (AM), is essential. In the UK, there are no data on the consistency or quality of the patient experience of AM, and no standardized definition and components of AM.

Methods: To understand the experience of patients and healthcare professionals (HCPs) of AM, a steering group was convened, including people with WM and HCPs who manage WM. A patient survey was designed by WMUK, a charity and patient organization supporting people with WM, to determine the quality and consistency of AM in WM in the UK. WMUK members completed the survey via email. To define a standard of care for AM, a survey of 40 Likert-scale statements across 6 clinical domains was created and distributed to HCPs and patients. Responses were used to create a consensus on recommendations on a new standard of care for AM in WM and a checklist to support patient-HCP discussions during consultations.

Results: *Patient experience of AM:* Among 168 survey respondents, most (34%) were aged 66-74 years; 150 (89%) lived in England, 11 (7%) in Scotland, 3 (2%) in Wales, and 4 (2%) in Northern Ireland. At the time of the survey, 108 (78%) respondents had been on AM for >2 years. Thirty-two (22%) did not receive an explanation of AM at diagnosis, 116 (69%) did not receive written information about AM, and 108 (64%) were not directed to support services during AM. Eighty-three (51%) respondents were not given information on disease progression symptoms for self-monitoring, and 105 (63%) stated that their AM experience could have been improved. *HCP/patient consensus on standards in AM:* Of 232 responses (189 [81%] people with WM; 43 [19%] HCPs), 39/40 statements attained very strong (≥90%) agreement. All statements met the agreement threshold (75%). Seven recommendations were created to define AM and minimum clinical standards of AM, the role and composition of the multidisciplinary team, and the need for educational materials and support from patient organizations. A patient checklist was also generated.

Conclusions: The patient experience of AM across the UK is highly variable, with more than half of participants stating their experience could be improved. The consensus statement provides a foundation for best clinical practice and communication of information during AM in WM.