

DETECTING MYELOMA – WAYS TO SHORTENING AN OFTEN PAINFUL AND TEDIOUS PATIENT ODYSSEY: RESULTS FROM AN INTERNATIONAL SURVEY CONDUCTED BY MYELOMA EURONET, THE EUROPEAN NETWORK OF MYELOMA PATIENT GROUPS

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Abstract

Background: It is well understood that a prolonged delay in myeloma diagnosis has a significant impact on disease-free survival. Myeloma can have various non-specific symptoms such as back pain, bone pain, bone fractures, recurrent infections, tiredness/weakness, and kidney problems. Patients therefore present to a range of medical professionals before their myeloma is detected, also including general practitioners/family doctors (GP/FD) and orthopaedic surgeons/traumatologists (OS/T). **Aims:** The aims of the study were to obtain information about the path patients take to myeloma diagnosis, what non-haematological/non-oncological medical professionals do to detect myeloma, the time necessary to detect myeloma, and steps required to avoid delays in myeloma diagnosis. **Methods:** A survey of 303 physicians from 56 countries (91.4% European), including 90 GP/FD (29.7%) and 206 OS/T (68.0%), was conducted via self-administered questionnaire including ten multiple-choice questions. In addition, 349 myeloma patients (MP) and myeloma patient relatives (MPR) from 37 countries of treatment (90.3% European), including 239 MP (68.5%) and 110 MPR (31.5%), completed a corresponding questionnaire with nine multiple-choice questions. **Results:** MP/MPR (n=236/109) stated the most frequent symptoms experienced before initial doctor consultation were back pain (45.8%/59.6%), tiredness/weakness (35.2%/37.6%), bone pain (26.7%/36.7%), recurrent infections (16.5%/17.4%), shortness of breath (14.4%/13.8%) and bone fractures (11.4%/11.9%). As a result, the most frequently consulted doctors according to MP/MPR (n=236/108) were GP/FD (64.4%/60.2%), haematologists (8.1%/5.6%) and OS (6.4%/5.6%). From there, MP/MPR (n=238/106) stated, the most frequent referrals were to haematologists (41.6%/24.5%), oncologists (10.5%/11.3%), OS (9.7%/11.3%), GP/FD (6.7%/7.5%) and rheumatologists (5.5%/6.6%). GP/FD (n=90) usually treat back pain (88.9%), tiredness/weakness, bone pain, shortness of breath (60.0% each), and recurrent infections (58.9%); OS/T (n=206) usually treat bone fractures (82.4%), bone pain (68.9%) and back pain (67.5%). Confronted with these symptoms, routine tests by GP/FD (n=89) include blood test (93.3%), x-ray of bones (75.3%) or urine test (68.5%); OS/T (n=204) would do x-ray of bones (90.7%), blood test (73.0%), MRI (51.0%) or CT scan (45.6%). However, 65.9% of GP/FD (n=88) and 47.5% of OS/T (n=202) were not very familiar/not familiar at all with myeloma, 80.7% of GP/FD (n=88) and 63.3% of OS/T (n=199) rarely/never detected myeloma, and 60.7% of GP/FD (n=89) and 46.8% of OS/T (n=201)

rarely/never referred patients to myeloma specialists. MP/MPR (n=230/108) stated that myeloma is mainly detected by haematologists (47.0%/47.2%), GP/FD (13.5%/10.2%), oncologists (8.3%/11.1%) and OS (6.1%/3.7%). According to MP/MPR (n=200/104), 44.5%/63.5% of patients received treatment for one/more symptoms before myeloma detection, including (n=89/66) pain treatment (33.7%/42.4%), physiotherapy/chiropractor/osteopath treatment (14.6%/21.2%) and orthopaedic interventions (11.2%/13.6%). According to MP/MPR (n=229/109), 76.0%/63.3% of patients saw 1-3 doctors before myeloma detection, and 23.1%/34.9% of MP/MPR stated it took 4 doctors or more to detect myeloma. According to MP/MPR (n=231/108), the average time for detecting myeloma is 186.8 days. According to GP/FD (n=89), OS/T (n=196) and MP/MPR (n=217/109), the most important steps to avoid delays in myeloma diagnosis are better information for (75.3%/71.9%/57.1%/67.9%), and better education of, medical professionals (53.9%/45.9%/40.1%/49.5%).

Summary/Conclusions: Little awareness of myeloma among GP/FD and OS/T most likely contributes to delays in myeloma diagnosis. Related information and education should concentrate on GP/FD.