

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



Anita Waldmann¹, Begoña Barragán², Viorica Cursaru³, Candy Heberlein⁴, Miroslav Hrianka, PhD⁵, Friedrich Richter⁶, Roman Sadžuga⁷

¹Leukaemihilfe Rhein-Main, Ruesselsheim, Germany, ²Asociación Española de Afectados por Linfomas, Mielomas y Leucemias, Madrid, Spain, ³Myeloma Euronet Romania, Bucharest, Romania, ⁴Stiftung zur Foerderung der Knochenmark-transplantation, Ebmingen, Switzerland, ⁵Slovenská myelómová spoločnosť, Bratislava/Žilina, Slovak Republic, ⁶Myelom- und Lymphomhilfe Oesterreich, Muellendorf, Austria, ⁷Polskie Stowarzyszenie Pomocy Chorym na Szpiczaka, Olsztyn, Poland

Introduction and Objectives: It is well understood that a prolonged delay in myeloma diagnosis has a significant impact on disease-free survival¹. 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).

The objectives of the study were to obtain information from physicians and patients about the path patients take to myeloma diagnosis, what medical professionals from different non-haematological and non-oncological medical specialties do to detect myeloma, how much time passes from initial consultation to myeloma diagnosis, and what should be done to avoid delays in myeloma diagnosis.

Methods: A survey of 303 physicians from 56 countries (91.4% European), including 90 GP/FD and 206 OS/T, was conducted during two international Orthopaedics/Traumatology and Primary Care congresses in June and September 2009 via self-administered questionnaire including ten multiple-choice questions. In addition, between July and December 2009, 349 myeloma patients (MP) and myeloma patient relatives (MPR) from 37 countries of treatment (90.3% European), including 239 MP and 110 MPR, completed a corresponding questionnaire with nine multiple-choice questions. Patient questionnaires were distributed by post and at local educational meetings and could also be completed online.

Results and Conclusions: 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%).** However, 65.9% of GP/FD (n=88) and 47.5% of OS/T (n=202) were not very familiar or not familiar at all with myeloma. **More than three-quarters of GP/FD (80.7%) and almost two-thirds of OS/T (63.3%) stated that they have rarely or never detected myeloma (figure 1),** and 60.7% of GP/FD (n=89) and 46.8% of OS/T (n=201) have rarely or never referred patients to myeloma specialists. MP/MPR (n=238/106) confirmed that less than half of the referrals following initial consultation were to haematologists (41.6%/24.5%), followed by oncologists (10.5%/11.3%), OS (9.7%/11.3%), GP/FD (6.7%/7.5%) and rheumatologists (5.5%/6.6%). 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%).

Experience detecting myeloma (in %)

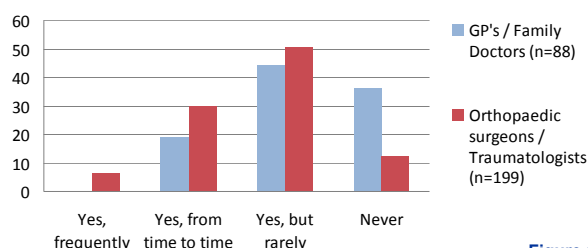


Figure 1

Time from initial consultation until myeloma was detected (in %)

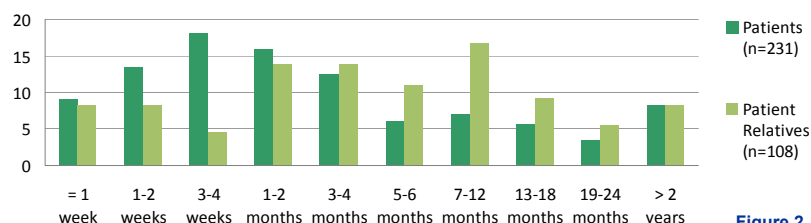


Figure 2

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. When combining the responses given by MP/MPR (n=231/108), **the average time for detecting myeloma is more than 6 months (186.8 days, figure 2).** GP/FD (n=89), OS/T (n=196) and MP/MPR (n=217/109) agreed that 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%).

The survey revealed that little awareness of myeloma among GP/FD and OS/T most likely contributes to delays in myeloma diagnosis. Given that the majority of initial consultations are with GP/FD, better information for, and education of, medical professionals should concentrate primarily on GP/FD.

The survey was made possible through an unrestricted grant from Celgene International.

References:

¹ Kariyawasan CC, Hughes DA, Jayatilake MM, Mehta AB: Multiple myeloma: causes and consequences of delay in diagnosis. QJM. 2007 Oct;100(10):635-40. Epub 2007 Sep 10.