## Supplementary Table 1: Definition of aspects of pain

|  |  |  |
| --- | --- | --- |
| **Aspects of pain** | **Questionnaire** | **Description and scoring** |
| **Physical pain** | EORTC-QLQ C30, questions 9 & 19  (Coordinator Q, 2001) | * Physical pain was based on the ***validated pain (P) score***, using responses to individual items on the presence of pain **and** if it interfered with daily activities during the past 7 days prior to the face-to-face consultation * ***A high P score corresponds to a high physical pain burden*** |
| EORTC-QLQ MY20, questions 31-36  (add-on to the EORTC-QLQ-C30)  (Coordinator Q, 2001) | * Physical pain was based on the ***validated disease symptoms (DS) score***, using responses to individual items indicating the presence of a site-specific pain (back, hip, arm/shoulder) **and** if pain increased with activity during the past 7 days prior to the face-to-face consultation * ***A high DS score corresponds to a high physical pain burden*** |
| **Social pain** | EORTC-QLQ C30, questions 26-27 (Coordinator Q, 2001) | * Social pain was based on the***validated social functioning (SF) score****,* using responses to individual items indicating interference with family life and social activities at the point of face-to-face consultation, and during the past 7 days prior to the face-to-face consultation * ***A high SF score corresponds to a low social pain burden*** |
| **Emotional pain** | EORTC-QLQ C30, questions 21-24 (Coordinator Q, 2001) | * Emotional pain was based on the ***validated emotional functioning (EF) score****,* using responses to individual items indicating effects on mood or response(s) about mental health status (anxiety or depression, worry) during the past 7 days prior to the face-to-face consultation * ***A high EF score corresponds to a low emotional pain burden*** |
| EORTC-QLQ MY20, questions 48-50  (add-on to the EORTC-QLQ-C30)  (Coordinator Q, 2001) | * Emotional pain was based on the ***validated future perspective (FP) score****,* using responses to individual items indicating effects on mood or response(s) about mental health status (anxiety or depression, worry) during the past 7 days prior to the face-to-face consultation * ***A high FP score corresponds to a low emotional pain burden*** |

## Supplementary Table 2: Thresholds for clinical importance for the EORTC QLQ-C30 scores

|  |  |
| --- | --- |
| **QoL score/domain** | **Threshold for clinical importance1** |
| EORTC QLQ-C30 Pain (PA) [Symptom scale] | 25 |
| EORTC QLQ-C30 Social functioning (SF) | 58 |
| EORTC QLQ-C30 Emotional functioning (EF) | 71 |
| 1Patient scores above TCI for symptom scales indicate a clinically important symptom, below TCI for functioning scales indicate a clinically important functional impairment (Giesinger et al. Thresholds for clinical importance were established to improve interpretation of the EORTC QLQ-C30 in clinical practice and research, *Journal of clinical epidemiology* 2019) | |

**Supplementary Table 3: Health-related quality of life by multiple myeloma patient self-reported pain severity**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Patient self-rated pain severity** | | | | | | ***p-*value*\**** |
|  | **All patients** | No pain | Mild pain | Moderate/severe pain | Moderate pain | Severe pain |
| n | 330 | 73 | 161 | 96 | 81 | 15 |  |
| Physical pain\*\* | | | | | | | |
| EORTC QLQ-C30 – Pain  (n) | | | | | | | |
| n | 330 | 73 | 161 | 96 | 81 | 15 |  |
| Mean (SD) | 35.91 (23.70) | 13.24 (15.46) | 35.40 (19.52) | 53.99 (19.90) | 54.12 (17.19) | 53.33 (31.62) | <0.0001 |
| EORTC QLQ-MY20 – Disease symptoms (n) | | | | | | | |
| n | 329 | 73 | 161 | 95 | 80 | 15 |  |
| Mean (SD) | 26.33 (17.58) | 10.23 (11.57) | 24.25 (14.38) | 42.23 (12.65) | 41.44 (12.71) | 46.44 (11.81) | <0.0001 |
| Social pain\*\* | | | | | | | |
| EORTC QLQ-C30 – Social functioning (n) | | | | | | | |
| n | 329 | 73 | 160 | 96 | 81 | 15 |  |
| Mean (SD) | 73.10 (24.00) | 81.05 (21.57) | 76.15 (20.87) | 61.98 (26.79) | 65.23 (26.38) | 44.44 (22.42) | <0.0001 |
| Emotional pain\*\* | | | | | | | |
| EORTC QLQ-C30 – Emotional functioning (n) | | | | | | | |
| n | 327 | 73 | 158 | 96 | 81 | 15 |  |
| Mean (SD) | 66.68 (20.73) | 78.08 (16.52) | 68.74 (18.83) | 54.60 (20.66) | 55.76 (21.39) | 48.33 (15.17) | <0.0001 |
|  | | | | | | | |
| EORTC QLQ-MY20 – Future perspective (n) | | | | | | | |
| n | 328 | 72 | 161 | 95 | 80 | 15 |  |
| Mean (SD) | 50.71 (29.50) | 67.13 (23.32) | 49.69 (31.16) | 40.00 (25.29) | 38.06 (25.67) | 50.37 (20.94) | <0.0001 |
| EORTC QLQ-MY20 – Have you been thinking about your illness? | | | | | | | |
| n | 328 | 72 | 161 | 78 | 80 | 15 |  |
| Mean (SD) | 2.55 (0.96) | 1.99 (0.78) | 2.65 (0.99) | 2.85 (0.88) | 2.84 (0.88) | 2.67 (0.90) | <0.0001 |
| EORTC QLQ-MY20 – Have you worried about dying? | | | | | | | |
| n | 327 | 72 | 161 | 77 | 79 | 15 |  |
| Mean (SD) | 2.32 (0.96) | 1.92 (0.76) | 2.32 (1.0) | 2.69 (0.96) | 2.70 (0.97) | 2.33 (0.62) | <0.0001 |
| EORTC QLQ-MY20 – Have you worried about your health in the future? | | | | | | | |
| n | 327 | 72 | 160 | 78 | 80 | 15 |  |
| Mean (SD) | 2.56 (0.99) | 2.06 (0.82) | 2.56 (1.06) | 3.05 (0.80) | 3.04 (0.80) | 2.47 (0.64) | <0.0001 |
| SD: standard deviation. EORTC scores in the table based on calculated scores as described in the methods. \* *p*-value is based on bivariate regression from regression model \*\*Overall subscale scores based on EORTC QLQ-C30 as described in methods. | | | | | | | |

**Supplementary Table 4: Level of agreement between symptoms reported by patients in self-reported symptoms list and EORTC-QLQ-MY20 (using Cohen's kappa analysis)**

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Patient reported symptoms experienced (a little, quite a bit, very much) from EORTC-QLQ MY20** | **Physician-reported symptoms** | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| **Bone pain** | | | | **Bone fractures** | | | | | **Lower back pain** | | | | | **Middle back pain** | | | | | **Rib pain** | | | | | **Hip pain** | | | | |
|  |  | N | Y | *p-*value | |  | N | Y | *p*-value | |  | N | Y | *p*-value | |  | N | Y | *p*-value | |  | N | Y | *p*-value | |  | N | Y | *p*-value |
| Bone aches or pain | N | 20.7% | 2.4% | <0.0001 | | N | 22.9% | 0.3% | 0.0414 | | N | 21.6% | 1.5% | 0.0001 | | N | 22.0% | 1.2% | 0.0035 | | N | 22.9% | 0.3% | 0.0194 | | N | 22.9% | 0.3% | 0.0006 |
| Y | 37.2% | 39.6% | Y | 72.0% | 4.9% | Y | 56.4% | 20.4% | Y | 63.1% | 13.7% | Y | 70.7% | 6.1% | Y | 65.2% | 11.6% |
|  | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Pain in back | N | 22.2% | 5.5% | <0.0001 | | N | 27.1% | 0.6% | 0.0662 | | N | 25.8% | 1.8% | <0.0001 | | N | 26.7% | 0.9% | 0.0001 | | N | 27.4% | 0.3% | 0.0077 | | N | 26.4% | 1.2% | 0.0048 |
| Y | 35.9% | 36.5% | Y | 67.8% | 4.6% | Y | 52.3% | 20.1% | Y | 58.4% | 14.0% | Y | 66.3% | 6.1% | Y | 61.7% | 10.6% |
|  | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Pain in chest | N | 38.6% | 28.0% | 0.5132 | | N | 62.9% | 3.6% | 0.641 | | N | 49.8% | 16.7% | 0.9772 | | N | 57.1% | 9.4% | 0.2978 | | N | 62.0% | 4.6% | 0.6873 | | N | 58.4% | 8.2% | 0.6465 |
| Y | 19.5% | 14.0% | Y | 31.9% | 1.5% | Y | 28.3% | 5.2% | Y | 28.0% | 5.5% | Y | 31.6% | 1.8% | Y | 29.8% | 3.6% |
|  | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Pain in hip | N | 29.3% | 14.3% | 0.0015 | | N | 41.8% | 1.8% | 0.2392 | | N | 38.4% | 5.2% | 0.0001 | | N | 38.4% | 5.2% | 0.0865 | | N | 42.1% | 1.5% | 0.0294 | | N | 42.7% | 0.9% | <0.0001 |
| Y | 28.7% | 27.7% | Y | 53.0% | 3.4% | Y | 39.6% | 16.8% | Y | 46.6% | 9.8% | Y | 51.5% | 4.9% | Y | 45.4% | 11.0% |
|  | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Pain in arm/shoulder | N | 34.3% | 22.2% | 0.129 | | N | 53.5% | 3.0% | 0.5775 | | N | 45.6% | 10.9% | 0.1028 | | N | 49.8% | 6.7% | 0.0374 | | N | 53.8% | 2.7% | 0.0956 | | N | 53.2% | 3.3% | 0.0001 |
| Y | 23.7% | 19.8% | Y | 41.3% | 2.1% | Y | 32.5% | 10.9% | Y | 35.3% | 8.2% | Y | 39.8% | 3.6% | Y | 35.0% | 8.5% |

**Supplementary Table 5: Level of agreement between symptoms (specifically pain) reported by patients and those recorded by the treating physician at their face-to-face clinical consultation (using Cohen's kappa analysis)**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Physician-reported pain severity** | **Patient-reported pain severity** | | | | | | | **Total (N, %)** |
| **No pain (N, %)** | **Mild pain (N, %)** | | **Moderate pain (N, %)** | | **Severe pain (N, %)** | |
|
| No pain N (%) | 62 (84.9%) | 91 (56.5%) | | 31 (38.3%) | | 7 (46.7%) | | 191 (57.9%) |
| Mild pain N (%) | 8 (11.0%) | 45 (28.0%) | | 17 (21.0%) | | 1 (6.7%) | | 71 (21.5%) |
| Moderate pain N (%) | 3 (4.1%) | 25 (15.5%) | | 31 (38.3%) | | 6 (40%) | | 65 (19.7%) |
| Severe pain N (%) | 0 (0%) | 0 (0%) | | 2 (2.5%) | | 1 (6.7%) | | 3 (.9%) |
| Total N (%) | 73 (100%) | 161 (100%) | | 81 (100%) | | 15 (100%) | | 330 (100%) |
| Expected agreement | Agreement | Kappa | | Standard Error | | Z | | Prob > Z |
| 67.50% | 75.80% | 0.2539 | | 0.0343 | | 7.41 | | 6.42E-14 |
|  |  | |  | |  | |  |  |
| Matched pain severity | 139 (42.1%) | |  | |  | |  |  |
| Patient rated higher pain severity than physician | 153 (46.4%) | |  | |  | |  |  |
| Physician rated higher pain severity than patient | 38 (11.5%) | |  | |  | |  |  |
| Each coefficient will indicate how the related group differs from the base case (no pain) | | |  | |  | |  |  |

**Supplementary Table 6: Level of agreement between symptoms reported by patients and those recorded by the treating physician at their face-to-face clinical consultation (using Cohen's kappa analysis)**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Concordence between physician and patient-reported symptoms** | | | | |
| **Physician/patient reported-symptoms** |
|
|  |  | | | **Kappa score** | ***p*-value** |
|  |  | N | Y |  |  |
| Bone pain | N | 38.2% | 19.7% | 0.4357 | <0.0001 |
| Y | 8.8% | 33.3% |
|  | | | | | |
| Bone fractures | N | 91.5% | 3.0% | 0.3179 | <0.0001 |
| Y | 3.6% | 1.8% |
|  | | | | | |
| Lower back pain | N | 51.5% | 26.4% | 0.2731 | <0.0001 |
| Y | 6.7% | 15.5% |
|  | | | | | |
| Middle back pain | N | 60.9% | 23.9% | 0.2622 | <0.0001 |
| Y | 4.8% | 10.3% |
|  | | | | | |
| Rib pain | N | 77.0% | 16.7% | 0.2366 | <0.0001 |
| Y | 2.1% | 4.2% |
|  | | | | | |
| Hip pain | N | 70.9% | 17.3% | 0.374 | <0.0001 |
| Y | 2.7% | 9.1% |
|  | | | | | |
| Abdominal pain | N | 91.8% | 6.4% | 0.3441 | <0.0001 |
| Y | 0.0% | 1.8% |
|  | | | | | |
| Bleeding | N | 90.6% | 3.6% | 0.2842 | <0.0001 |
| Y | 3.9% | 1.8% |
|  | | | | | |
| Bruising | N | 91.5% | 2.7% | 0.4125 | <0.0001 |
| Y | 3.3% | 2.4% |
|  | | | | | |
| Pallor/pale skin | N | 70.0% | 4.5% | 0.362 | <0.0001 |
| Y | 16.1% | 9.4% |
|  | | | | | |
| Pruritus/itchy skin | N | 84.5% | 9.1% | 0.1743 | 0.0004 |
| Y | 4.2% | 2.1% |
|  | | | | | |
| Tingling of hands or feet | N | 74.2% | 12.1% | 0.3173 | <0.0001 |
| Y | 6.7% | 7.0% |
|  | | | | | |
| Numbness | N | 91.2% | 5.2% | 0.4031 | <0.0001 |
| Y | 1.2% | 2.4% |
|  | | | | | |
| Confusion | N | 97.3% | 1.5% | 0.1882 | 0.0002 |
| Y | 0.9% | 0.3% |
|  | | | | | |
| Indigestion | N | 86.1% | 8.8% | 0.1368 | 0.0039 |
| Y | 3.6% | 1.5% |
|  | | | | | |
| Nausea | N | 77.9% | 9.4% | 0.4096 | <0.0001 |
| Y | 5.5% | 7.3% |
|  | | | | | |
| Vomiting | N | 93.6% | 2.7% | 0.1441 | 0.0044 |
| Y | 3.0% | 0.6% |
|  | | | | | |
| Early satiety | N | 90.6% | 5.2% | 0.1872 | 0.0003 |
| Y | 3.0% | 1.2% |
|  | | | | | |
| Loss of appetite | N | 67.9% | 10.0% | 0.3476 | <0.0001 |
| Y | 11.8% | 10.3% |
|  | | | | | |
| Constipation | N | 90.6% | 6.4% | 0.1937 | <0.0001 |
| Y | 1.8% | 1.2% |
|  | | | | | |
| Weight loss | N | 70.9% | 7.3% | 0.4205 | <0.0001 |
| Y | 11.2% | 10.6% |
|  | | | | | |
| Shortness of breath | N | 81.5% | 10.3% | 0.0902 | 0.0466 |
| Y | 6.4% | 1.8% |
|  | | | | | |
| Fatigue | N | 46.1% | 13.0% | 0.3417 | <0.0001 |
| Y | 18.2% | 22.7% |
|  | | | | | |
| Cough/sore throat | N | 95.2% | 3.6% | 0.2073 | <0.0001 |
| Y | 0.6% | 0.6% |
|  | | | | | |
| Fever | N | 93.9% | 2.1% | 0.2347 | <0.0001 |
| Y | 3.0% | 0.9% |
|  | | | | | |
| Headaches | N | 87.0% | 8.2% | 0.1536 | 0.0014 |
| Y | 3.3% | 1.5% |
|  | | | | | |
| Blurred vision | N | 96.4% | 1.5% | 0.1369 | 0.0063 |
| Y | 1.8% | 0.3% |
|  | | | | | |
| Dizziness/poor balance | N | 94.5% | 3.0% | -0.0277 | 0.6936 |
| Y | 2.4% | 0.0% |
|  | | | | | |
| Increased thirst | N | 91.8% | 4.5% | 0.4299 | <0.0001 |
| Y | 1.2% | 2.4% |
|  | | | | | |
| Increased urination | N | 93.6% | 1.5% | 0.6277 | 0 |
| Y | 1.8% | 3.0% |
|  | | | | | |
| Decreased urination | N | 97.3% | 0.9% | -0.0123 | 0.5936 |
| Y | 1.8% | 0.0% |
|  | | | | | |
| Oedema | N | 91.2% | 1.8% | 0.4833 | 0 |
| Y | 3.9% | 3.0% |
|  | | | | | |
| Restlessness | N | 85.5% | 7.0% | 0.2203 | <0.0001 |
| Y | 5.2% | 2.4% |
|  | | | | | |
| Impotence | N | 96.1% | 2.4% | 0.2515 | <0.0001 |
| Y | 0.9% | 0.6% |