**APPENDIX**

**FIGURE A**

**Questionnaire for patients:**

* “*Before the treatment, you mentioned the following treatment goals. To what extent are these goals achieved on a scale of 0 to 10*?”

1.\_[Goal 1 is written here]\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

0 1 2 3 4 5 6 7 8 9 10

not achieved at all highly achieved

2.\_[Goal 2 is written here \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

0 1 2 3 4 5 6 7 8 9 10

not achieved at all highly achieved

3.\_[Goal 3 is written here]\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

0 1 2 3 4 5 6 7 8 9 10

not achieved at all highly achieved

4.\_[Goal 4 is written here]\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

0 1 2 3 4 5 6 7 8 9 10

not achieved at all highly achieved

- “*In retrospect, did you receive enough information on the treatment*?”

Too much/ enough/ not enough

This is what I missed: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

* “*In hindsight, do you think the right decision was made for treatment*?”

Yes/ No / I don’t know for sure

* *Did the treatment goals you had before the start of treatment, change during treatment?*
  + Yes, namely
  + No

**Questionnaire for oncologists:**

* “*Before your patient started the treatment, you mentioned the following treatment goals. To what extent are these goals achieved on a scale of 0 to 10*?”

1.\_[Goal 1 is written here]\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

0 1 2 3 4 5 6 7 8 9 10

not achieved at all highly achieved

2.\_[Goal 2 is written here \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

0 1 2 3 4 5 6 7 8 9 10

not achieved at all highly achieved

3.\_[Goal 3 is written here]\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

0 1 2 3 4 5 6 7 8 9 10

not achieved at all highly achieved

4.\_[Goal 4 is written here]\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

0 1 2 3 4 5 6 7 8 9 10

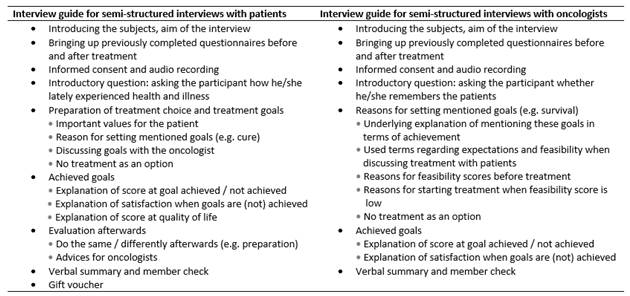
not achieved at all highly achieved

* “*In hindsight, do you think the right decision was made for treatment?*?”

Yes/ No / I don’t know for sure

|  |  |
| --- | --- |
| TABLE A – Examples of treatment goals from patients and oncologists | |
| **Category** | **English** |
| Quality of life | Having a more comfortable life |
|  | Better quality of life |
|  | Better mobility |
|  | Feeling better |
|  | Being able to do more things than I can do now |
|  | The best quality of life |
|  | Making the quality of life as high as possible |
|  | Having a bearable life |
|  | Having a pleasant life |
|  | Good quality of life |
|  | Quality of life |
|  | Improve quality of life |
|  | Improve life |
|  | Strive for a better life than I have now |
|  | Living life to the fullest |
|  | Pain relieve |
|  | Improvement |
|  | Improve life circumstances |
|  | Relieve dyspnoea |
|  | Less symptoms |
|  | More oxygen |
|  | Less pleural effusion |
|  | Being less ill |
|  |  |
| Decrease in tumour size | Decrease tumour carcinoma |
|  | Slow down tumour |
|  | Slow down metastases |
|  | Restriction of tumours |
|  | To stop cancer cells from growing |
|  | To stop the cancer |
|  | To prevent the cancer from growing |
|  | To control cancer |
|  | That the cancer disappears |
|  | To decrease the tumour cells |
|  | That the tumour disappears |
|  | That it does not grow any further |
|  | High stabilization of the disease |
|  | To fight the cancer |
|  | Prevent new metastases |
|  | To stop the tumour from growing |
|  | To delay the cancer process |
|  | To stop the cancer |
|  | Stopping the disease process |
|  | To shrink the tumour |
|  | To slow down the disease |
|  | To slow down the cells |
|  | Staying stable |
|  | Stop the cancer |
|  | To withhold the tumour |
|  | To shrink the tumour |
|  | To delay the growth |
|  |  |
| Life prolongation | Better life opportunities |
|  | To live longer |
|  | To enjoy time with my partner as long as possible |
|  | A future |
|  | Extra time |
|  | To live longer |
|  | Longer lifespan |
|  | To prolong life |
|  | Life prolongation |
|  | More time |
|  | To live as long as possible |
|  | Time gain |
|  | Postpone death |
|  | To prolong life |
|  |  |
| Cure | Getting better |
|  | That I recover |
|  | Cured |
|  | Recovery |
|  | Regain one’s health |
|  | Prefer speedy recovery |
|  | Gain health |
|  |  |
| Other | Visiting Suriname |
|  | Nothing |
|  | To keep the option for radiation |
|  | To quit |
|  | To do everything about it |
|  | Improve medication for future patients |
|  | To contribute to science |
|  | So that specialists can learn |
|  | To have the feeling I have tried everything |
|  | Gain more insight in research |
|  | To keep the option for immunotherapy |

**TABLE B.**



|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| TABLE C – Comparison of patients who filled out questionnaire or not | | | |  |
|  | **Filled out questionnaire** | **Did not filled out questionnaire** | | |
| N=240  Variable (N)  (column %) | **Patients who filled out N=146** | **Patients who died N=72** | **Patients who declined N=22** | **P-value** |
| Age – Years  <60 (71)  61-70 (102)  ≥ 71 (67) | 33  42  25 | 26  42  32 | 14  50  36 | 0.311 |
| Sex  Male (131)  Female (109) | 57  43 | 54  46 | 41  59 | 0.374 |
| Marital status  Married (186)  Unmarried (54) | 78  22 | 79  21 | 68  32 | 0.538 |
| Comorbidity  Yes (154)  No (79) | 63  37 | 67  33 | 81  19 | 0.227 |
| ECOG performance score  0 (35)  1 (111)  ≥ 2 (60) | 22  55  23 | 3  51  **46** | 21  53  26 | **0.005** |
| Tumour histology  SCLC (13)  NSCLC without targetable driver mutation (170)  NSCLC with targetable driver mutation (57) | 6  67  27 | 4  75  21 | 9  82  9 | 0.324 |
| Type of systemic treatment  Chemotherapy (94)  Immunotherapy (116)  TKIs (30) | 42  44  14 | 35  53  12 | 36  59  5 | 0.524 |
| Line of treatment  1st (99)  2nd (103)  ≥ 3rd (38) | 40  41  19 | 43  46  11 | 46  46  8 | 0.525 |
| Hospital type  Academic (177)  Non-academic (63) | 73  27 | 69  31 | 91  9 | 0.132 |

|  |  |  |  |
| --- | --- | --- | --- |
| TABLE D - Univariate and multivariate GEE analyses of factors associated with achievement of treatment goals according to patients | | | |
| **N=219**  **Variable (N)** | **Goal achieved (≥6) according to patient (row %)** | **Univariate**  **OR (95%-CI)** | **Multivariate**  **OR (95%-CI)** |
| **Age - Years**  **≤60 (76)**  **61-70 (100)**  **≥71 (43)** | 40  53  56 | 1.0  1.661 (0.908 – 3.041)  **1.937 (0.908 – 4.131)** | 1.0  **4.938 (2.249 – 10.846)**  **3.098 (1.174 – 8.178)** |
| **Sex**  **Male (126)**  **Female (93)** | 49  47 | 1.097 (0.675 – 1.785)  1.0 |  |
| **Marital status**  **Married (179)**  **Unmarried (40)** | 48  50 | 0.920 (0.512 – 1.652)  1.0 |  |
| **Education**  **Low (47)**  **Middle (95)**  **High (60)** | 51  46  47 | 1.0  0.775 (0.361 – 1.662)  0.904 (0.309 – 2.639) |  |
| **Religious**  **Yes (88)**  **No (131)** | 44  51 | 1.0  1.365 (0.473 – 3.942) |  |
| **Comorbidity**  **Yes (135)**  **No (76)** | 52  46 | 1.341 (0.646 – 2.781)  1.0 |  |
| **ECOG performance score**  **0 (39)**  **1 (111)**  **≥ 2 (46)** | 54  47  46 | 1.0  0.848 (0.323 – 2.225)  0.755 (0.291 – 1.959) |  |
| **Quality of life (mean ± stdev)** | 4.6 ± 1.6 | **1.927 (1.482 – 2.507)** | **2.001 (1.501 – 2.667)** |
| **Tumour histology**  **SCLC (13)**  **NSCLC without targetable driver mutation (152)**  **NSCLC with targetable driver mutation (54)** | 46  50  44 | 1.0  1.247 (0.168 – 9.248)  1.056 (0.151 – 7.375) |  |
| **Type of systemic treatment**  **Chemotherapy (92)**  **Immunotherapy (100)**  **TKIs (27)** | 53  47  37 | 1.0  0.684 (0.289 – 1.617)  **0.516 (0.262 – 1.018)** | 1.0  0.489 (0.165 – 1.446)  **0.277 (0.091 – 0.847)** |
| **Line of treatment**  **1st (84)**  **2nd (96)**  **≥ 3rd (39)** | 55  45  55 | 1.0  **0.615 (0.355 – 1.067)**  0.642 (0.238 – 1.731) |  |
| **Treatment duration**  **<2 months (95)**  **2-6 months (64)**  **> 6 months (60)** | 31  55  70 | 1.0  **2.617 (1.323 – 5.179)**  **4.966 (1.871 – 13.185)** | 1.0  2.176 (0.990 – 4.785)  **6.449 (2.632 – 15.802)** |
| **Hospital type**  **Academic (164)**  **Non-academic (55)** | 49  46 | 1.169 (0.526 – 2.595)  1.0 |  |
| **Treatment goal**  **Quality of life (69)**  **Decrease in tumour size (70)**  **Cure (27)**  **Life prolongation (53)** | 46  39  44  66 | 1.0  0.792 (0.321 – 1.955)  0.950 (0.424 – 2.133)  **2.233 (1.134 – 4.337)** |  |

|  |  |  |  |
| --- | --- | --- | --- |
| TABLE E - Univariate and multivariate GEE analyses of factors associated with achievement of treatment goals according to oncologists | | | |
| **N=428**  **Variable (N)** | **Goal achieved (≥6) according to oncologists (row %)** | **Univariate**  **OR (95%-CI)** | **Multivariate**  **OR (95%-CI)** |
| **Age - Years**  **≤60 (120)**  **61-70 (182)**  **≥71 (124)** | 55  37  53 | 1.0  **0.489 (0.266 – 0.900)**  0.846 (0.576 – 1.242) |  |
| **Sex**  **Male (226)**  **Female (202)** | 46  49 | 1.0  1.068 (0.632 – 1.806) |  |
| **Marital status**  **Married (337)**  **Unmarried (90)** | 45  53 | 1.0  1.323 (0.843 – 2.077) |  |
| **Education**  **Low (79)**  **Middle (186)**  **High (107)** | 57  42  53 | 1.0  **0.685 (0.444 – 1.056)**  1.133 (0.443 – 2.894) |  |
| **Religious**  **Yes (167)**  **No (261)** | 46  48 | 1.0  1.088 (0.652 – 1.815) |  |
| **Comorbidity**  **Yes (272)**  **No (142)** | 44  49 | 1.0  1.359 (0.609 – 3.030) |  |
| **ECOG performance score**  **0 (60)**  **1 (194)**  **≥ 2 (105)** | 62  49  34 | 1.0  **0.573 (0.348 – 0.942)**  **0.310 (0.142 – 0.678)** | 1.0  **0.468 (0.217 – 1.009)**  **0.338 (0.114 – 1.000)** |
| **Quality of life (mean ± stdev)** | 4.6 ± 1.6 | **1.518 (1.286 – 1.792)** |  |
| **Tumour histology**  **SCLC (25)**  **NSCLC without targetable driver mutation (296)**  **NSCLC with targetable driver mutation (107)** | 56  42  60 | 1.0  0.673 (0.241 – 1.880)  1.358 (0.376 – 4.902) |  |
| **Type of systemic treatment**  **Chemotherapy (175)**  **Immunotherapy (192)**  **TKIs (61)** | 46  40  72 | 1.0  0.711 (0.287 – 1.761)  **2.869 (1.461 – 5.634)** | 1.0  **0.356 (0.153 – 0.829)**  0.651 (0.171 – 2.478) |
| **Line of treatment**  **1st (196)**  **2nd (174)**  **≥ 3rd (58)** | 49  43  53 | 1.0  0.783 (0.437 – 1.401)  1.046 (0.534 – 2.047) |  |
| **Treatment duration**  **<2 months (183)**  **2-6 months (133)**  **> 6 months (106)** | 14  55  92 | 1.0  **6.817 (3.747 – 12.403)**  **72.613 (19.245 – 273.970)** | 1.0  **7.356 (3.298 – 16.407)**  **134.476 (25.721 – 703.069)** |
| **Patients who died during treatment**  **Yes (114)**  **No (314)** | 34  52 | 1.0  **2.114 (1.207 – 3.702)** |  |
| **Hospital type**  **Academic (309)**  **Non-academic (119)** | 47  47 | 1.006 (0.452 – 2.237)  1.0 |  |
| **Treatment goal**  **Quality of life (171)**  **Decrease in tumour size (140)**  **Life prolongation (117)** | 45  49  47 | 1.0  1.111 (0.834 –1.480)  1.065 (0.868 – 1.307) |  |