**Supplemental Data**

Supplemental data 1. Semi-structured interview guide

| ***Interview domains*** | ***Sample questions*** |
| --- | --- |
| Illness experience | Tell me about how MSA has affected your life. |
|   | Has anything changed for the better in your life since the diagnosis of MSA? |
|   | Can you envision what the future looks like? |
| Diagnosis experience | I want to take you back to when you got your diagnosis of Multiple System Atrophy. Was there anything that was done really well about how the diagnosis was given? |
|   | Is there anything that could have been done differently or better? |
|   | What was helpful at that time? |
|   | How did you get the information you needed about MSA? |
|  | How did the information make you feel? |
|  | If you could give a message to neurologists about giving the diagnosis, what would it be? |
| Patient symptoms | What has been the most troublesome MSA symptom for you? |
|   | Has your team tried to help you with that? |
|   | What has worked for you? |
|   | If you could resolve two symptoms that would greatly improve your quality of life, which ones would you say they are? |
| Supports and services | Who are some health professionals you found helpful in dealing with your MSA? |
|  | Have you had any negative health care experiences related to your MSA? |
|  | Do you have help from home care paid for by the government? |
|  | What was accessing home care, if applicable, like? |
|  | Do you have help from home care that you pay for? |
|   | Do you have help from family members? |
|  | Do you have help from friends, neighbors, members of your religious community? |
|  | What challenges do you/your loved one face in day-to-day life? |
|  | Are there challenges in coordinating appointments and in-home care? |
|  | What was accessing equipment (such as walkers and lifts) like? |
|  | What about devices such as PEG tubes and catheters? |
|  | Are there any services that you don’t currently have access to that would be useful? |
| Caregiving experience | What has your experience of being a caregiver been like? |
|   | What supports do you have as a caregiver? |
|   | Are there any supports or services you feel would be useful to you as a caregiver?How has MSA changed the relationship between you and your spouse or loved one? |
| Other | Is there anything else that I haven’t asked about that you would like to add about your experience? |
|   | Is there anything from the surveys that you answered earlier you’d like to expand on? |
|  | Is there a question I should add to this interview? |

Supplemental data 2. SF-36 scores of PwMSA as rated by PwMSA and caregivers

|  |  |  |
| --- | --- | --- |
|  | Self-rated by PwMSA | Rated by caregivers  |
| *n* | 9 | 11 |
| Physical functioning | 24.44 ± 30.46 | 6.82 ± 9.29 |
| Role limitations due to physical health | 5.56 ± 11.02 | 0.00 ± 0.00 (*n*=10) |
| Role limitations due to emotional problems | 33.33 ± 44.10 | 20.00 ± 35.84 (*n*=10) |
| Energy/fatigue | 24.44 ± 18.62 | 25.00 ± 18.44 |
| Emotional well-being | 54.67 ± 20.88 | 59.64 ± 17.01 |
| Social functioning | 40.28 ± 27.08 | 25.00 ± 25.00 |
| Pain | 55.83 ± 32.93 | 42.25 ± 31.30 (*n*=10) |
| General health | 32.78 ± 22.24  | 22.27 ± 20.66 |
| Health change | 13.89 ± 18.16 | 11.36 ± 13.06 |
| Physical Component Score (PCS) | 25.81 ± 11.26 | 18.44 ± 4.71 (*n*=10) |
| Mental Component Score (MCS) | 35.30 ± 15.91 | 36.65 ± 11.67 (*n*=10) |

Supplemental data 3. MSA-QoL scores of PwMSA as rated by PwMSA and caregivers

|  |  |  |
| --- | --- | --- |
|  | Self-rated by PwMSA | Rated by caregivers  |
| *n* | 9 | 11 |
| MSA-QoL motor subscale | 74.63 ± 8.82 | 75.01 ± 19.22 |
| MSA-QoL non-motor subscale | 55.82 ± 15.09 | 60.12 ± 20.23 |
| MSA-QoL emotional/social functioning subscale | 49.64 ± 15.82 | 62.67 ± 23.29 |
| MSA-QoL visual analog scale | 35.00 ± 21.31 | 40.36 ± 26.85 |

Supplemental data 4. HADS scores of PwMSA as rated by PwMSA and caregivers

|  |  |  |
| --- | --- | --- |
|  | Self-rated by PwMSA | Rated by caregivers  |
| *n* | 8 | 11 |
| HADS anxiety score | 8.38 ± 4.81 (n=8) | 10.97 ± 6.19 (n=11) |
| HADS depression score | 10.13 ± 4.79 (n=8) | 12.45 ± 5.09 (n=11) |