**Appendix 1: Questionnaire about the Needs of Family Caregivers**

In this questionnaire, we provided participants with the following list of needs, and asked them to report how important each need is for family caregivers (from 0 “not at all important to 10 “extremely important”) and how the need has been met for family caregivers (“no need”, “unmet need”, “partially met need”, or “met need”).

1) Information on dementia and what to expect as the illness progresses

2) Information on treatment for dementia

3) Information on services for people with dementia

4) Information on services for caregivers

5) Information on planning for the future (e.g., moving to a nursing home, end-of-life decisions)

6) Information that is easier to understand or is given in another language; i.e., other than English

7) Access to a real person who can provide information when it's needed

8) Emotional support for caregivers from family and friends

9) Emotional support for caregivers from other people who are caring for someone with dementia

10) Therapy for caregivers to manage stress, depression, and anxiety

11) Someone for caregivers to talk to about concerns around their changing relationship, guilt, frustration, or fears about the future

12) Help caring for caregivers' physical health

13) Time for caregivers to take care of themselves

14) Time for caregivers to care for people other than the person with dementia (e.g., children or grandchildren)

15) Help for caregivers to balance work and caring responsibilities

16) Help with basic care tasks for the person with dementia (e.g., giving a bath, dressing, helping use the toilet, moving, or lifting)

17) Help with household chores for the person with dementia (e.g., preparing meals; shopping, housecleaning, or banking; helping with medications)

18) Help keeping the person with dementia safe at home

19) Help advocating for the person with dementia in the health care system

20) Help providing emotional support to the person with dementia

21) Help finding activities that the person with dementia will enjoy

22) Help communicating with the person with dementia and understanding his/her needs

23) Help for the person with dementia to manage his/her memory and other cognitive problems

24) Information and training to help caregivers manage the person with dementia's mood or behaviour problems (e.g., wandering, acting different, crying, or screaming)

25) Help making decisions and managing conflicts with other family and friends involved in care

26) Access to early diagnosis and consultation when the symptoms of dementia first start

27) Help choosing the right home care services

28) Help coordinating and organizing the care that the person with dementia is currently receiving

29) Timely access to a doctor or other health care professional when a question or concern arises about the health of the person with dementia

30) Access to health services at night or on weekends

31) Health care services close to home

32) Services that cater to the person with dementia's ethnic or cultural background

33) Help figuring out what to do in a crisis

34) Financial assistance (e.g., tax breaks, more access to government-funded services)

35) Legal assistance (e.g., figuring out wills or a power of attorney for the care recipient)

36) Understanding from family and friends about the challenges of caregiving for a person with dementia

37) Understanding from health care professionals about the challenges of caregiving for a person with dementia

38) Understanding from the community and broader society about the challenges of caregiving for a person with dementia

39) Other (Please specify here \_\_\_\_\_\_\_\_\_)

Here is the example of the first page of the questionnaire for family caregivers.

*Below are some needs that caregivers of people with dementia sometimes report. We want to know how important each need is to you (from 0 = not at all important to 10 = extremely important) and we want to know whether this need has been met for you in the last 12 months. You will have the chance to add additional needs at the end of the list if something important to you was not mentioned.*

*I need…*

|  | **How important is this need to you?** | **Has this need been met for you?** |
| --- | --- | --- |
| 1. Information on dementia and what to expect as the illness progresses | |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | 0 | 1 | 2 | 3 | 4 | 5 | | 6 | 7 | 8 | 9 | 10 | | Not at all  important | | | | | | Extremely  important | | | | | | | | |  |  |  |  | | --- | --- | --- | --- | | No need | Unmet need | Partially met need | Met need | |
| 1. Information on treatment for dementia | |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | |  |  |  |  | | --- | --- | --- | --- | | No need | Unmet need | Partially met need | Met need | |
| 1. Information on services for people with dementia | |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | |  |  |  |  | | --- | --- | --- | --- | | No need | Unmet need | Partially met need | Met need | |