Supplement A. Phase 2 findings: Items selected and revised for the questionnaire (n=30).

| Revised Item # | Previous Item # | Domain | Trait | Core Concept | Indicator | Revised Item |
|----------------|-----------------|--------|-------|--------------|-----------|--------------|
| 1              | Q7              | Med    | Cog   | Control      | Knowing about current health status | I believe I understand my family member’s current health status. |
| 2              | Q2              | Med    | Cog   | Control      | Knowing the trajectory of dementia | I believe I know what changes to expect as dementia advances. |
| 3              | Q4              | Med    | Cog   | Control      | Knowing what decisions may be needed | I understand I may be faced with decisions such as: transferring to hospital, treating infections. |
| 4              | Q9              | Med    | Cog   | Oblig        | Knowing the PWD’s goals | I believe I know what treatments my family member would choose. |
| 5              | Q10             | Med    | Beh   | Control      | Discussing goals with staff | I have shared my family member’s goals with health care providers, for example: focusing on living longer, maximizing comfort. |
| 6              | Q11             | Med    | Beh   | Control      | Discussing goals with family | I have discussed end-of-life care preferences with my family members. |
| 7              | Q12             | Med    | Beh   | Control      | Discussing care preferences with staff | Health care providers and I have discussed our end-of-life care preferences for my family member, for example: location, pain management. |
| 8              | Q17             | Med    | Cog   | Control      | Knowing about the dying process | I have learned what the dying process may be like. |
| 9              | Q3              | Med    | Adapt | Aff           | Knowing that dementia is incurable | I understand that dementia (including Alzheimers) is a terminal condition. |
| Revised Item # | Previous Item # | Domain | Trait | Core Concept | Indicator | Revised Item |
|----------------|----------------|--------|-------|--------------|-----------|--------------|
| 10             | Q23, 24        | Rel    | Beh   | Control      | Organizing care | I believe I can carry out my responsibilities, for example: decision-maker, companion, advocate. |
| 11             | Q25            | Rel    | Beh   | Control      | Managing the situation | *I would like to be more in control over my family member’s situation. |
| 12             | Q43            | Rel    | Aff   | Adapt        | Accepting personal limitations | I accept that I am doing my best for my family member. |
| 13             | Q29, 35        | Rel    | Aff   | Adapt        | Having emotional support from staff and family | I have someone to go to for emotional support when my family member is dying. |
| 14             | Q33            | Rel    | Cog   | Adapt        | Knowing what emotions to expect | I understand what my grief process may be like after my family member has died. |
| 15             | Q22, 30        | Rel    | Aff   | Adapt        | Concern over conflict with staff or family/friends | *I worry that disagreements will make my family member’s death more difficult, for example: with family, friends, health care providers. |
| 16             | Q36            | Rel    | Beh   | Adapt        | Reconciling and closing the relationship with the PWD | I am making the most of my time with my family member, for example: by saying what I need to say to them. |
| 17             | Q50            | Spirit | Beh   | Oblig        | Helping to complete life | I am helping my family member with activities they would want near end-of-life, for example: seeing old friends. |
| Revised Item # | Previous Item # | Domain | Trait | Core Concept | Indicator                                                                 | Revised Item                                                                 |
|----------------|-----------------|--------|-------|--------------|---------------------------------------------------------------------------|--------------------------------------------------------------------------------|
| 18             |                 | Spirit | Beh   | Adapt        | Reflecting on the PWD’s life and legacy                                   | I am spending time reflecting on my family member’s life, for example: by sharing stories. |
| 19             |                 | Spirit | Beh   | Oblig        | Planning to follow spiritual/ cultural/ personal traditions or beliefs    | I have a plan to honour traditions or practices my family member would want, for example: cultural, spiritual, religious. |
| 20             |                 | Spirit | Beh   | Control      | Discussing spiritual care with staff                                      | I have discussed our family’s practices or traditions with health care providers, for example: privacy, prayers, opening a window. |
| 21             |                 | Spirit | Aff   | Adapt        | Feeling spiritually supported                                            | I have someone I can talk to about the meaning of illness or dying. |
| 22             |                 | Spirit | Aff   | Adapt        | Feeling life will have purpose after death                               | *I worry about having purpose in my life after my family member is gone. |
| 23             |                 | Spirit | Beh   | Adapt        | Coping with emotions                                                     | I am practicing activities which give me strength such as: spending time in nature. |
| 24             | Q65, 66, 67     | Pract  | Beh   | Oblig        | Organizing affairs                                                       | My family member's affairs are in order, for example: decision-maker, will, banking, credit cards, insurance. |
| 25             |                 | Pract  | Aff   | Adapt        | Having support for family affairs                                        | I have someone I can contact if I need help managing my family member’s affairs. |
| 26             |                 | Pract  | Cog   | Control      | Knowing how to contact family/friends after death                         | I know how to notify family and friends when my family member dies. |
| Revised Item # | Previous Item # | Domain | Trait | Core Concept | Indicator | Revised Item |
|---------------|-----------------|--------|-------|--------------|-----------|--------------|
| 27            | Q59             | Pract  | Beh   | Oblig        | Arranging after-death services for the body | After-death services are arranged for my family member, such as: burial or cremation. |
| 28            | Q70             | Pract  | Beh   | Adapt        | Feeling confident you can manage your personal household affairs | I believe I can manage my personal affairs after my family member is gone, for example: finances, housing. |
| 29            | Q64, 69         | Pract  | Cog   | Oblig        | Knowing about after-death processes | I am aware of after-death policies I will need to follow, for example: moving belongings in long-term care. |
| 30            | Q60             | Pract  | Beh   | Oblig        | Arranging practices to close the PWD’s life | I am thinking about memorials appropriate for our family such as: gathering, funeral, celebration, private time. |

Note: Abbreviations. Domains/subscales: Med=medical; Rel=relationships/personal; Spirit=spiritual; Pract=practical. Traits: Cog=cognitive; Beh=behaviour; Aff=affective; Global=all traits; Core Concepts, Control=managing the situation; Oblig=fulfilling obligations; Adapt=adapting to loss. *=reverse coded (i.e., negatively worded) item. 1=Item previously included in spiritual domain, moved to relationship/personal domain.