

Supplementary Material

A Conceptual Model to Improve Care for Individuals with Alzheimer’s Disease and Related Dementias and Their Caregivers: Qualitative Findings in an Online Caregiver Forum

Supplementary Table 1. Frequencies of themes, sub-themes, and codes.

Themes, Sub-themes and Codes	Code Frequency
1. Individual with ADRD	
<i>1a. ADRD effect on individual with ADRD</i>	
Capabilities and functioning	114
Stage and/or diagnosis of ADRD	65
<i>1b. Health and medications of individual with ADRD</i>	
Pharmacotherapy	49
Confounding illness	40
Hospitalization	11
2. Caregiver	
<i>2a. Handling of the caregiving role and support within it</i>	
Information support	196
Emotional support	182
Emotions associated with caregiving	74
Spirituality/Religion	52
Emotions associated with loss	40
Self-care	34
Presence of offline social support	12
Coping techniques	11
<i>2b. Effects of caregiving on the caregiver</i>	
Caregiver burden	73
Caregiver: physical and mental health	34
Life balance	22
Effects of caregiving on family	17
3. Dynamic Between Caregiver and Individual with ADRD	
<i>3a. Caregiver decisions impacting individual with ADRD</i>	
Medical decisions	70
Moral dilemma	59
Facility placement	36
Supplemental products/therapies	6
<i>3b. Caregiving role and individual with ADRD</i>	
Caregiving strategies	75
Ensuring comfort	67
Caregiver reflection of LO past	24
Unrealistic expectations	9
Consequences of unmonitored ADRD	2

<i>3c. Behavioral and psychological symptoms of ADRD affecting the caregiver</i>	
Challenging behavior	72
Mental health	72
Progression speed/realization	52
Anosognosia and/or compliance issues	46
Eating behavior	31
LO dependency	4
False hope	2
<i>3d. Relationship between the caregiver and individual with ADRD</i>	
Relationship between caregiver and care recipient	38
Finding purpose in caregiving	9
4. Context of Care	
<i>4a. Managerial aspects of care</i>	
Logistics of care	67
Finances	66
Legal matters	41
<i>4b. Care and caregiving arrangements</i>	
Supplemental care/services in caregiving role	60
Living arrangement/relocation	44
Remote caregiving	22
Last resort alternative	2
Family involvement	68
End of life care/stage	47
<i>4c. Physical environment and activities</i>	
Environment and safety	39
Activities and stimulation	28
Visiting and/or routine	22
<i>4d. Healthcare context</i>	
Quality of healthcare	33
Problems with healthcare system	3