

Research Article

# Psychosocial Stressors and Adaptive Coping Strategies in Couples After a Diagnosis of Young-Onset Dementia

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## Abstract

**Background and Objectives:** Diagnoses of young-onset dementias (YODs) are devastating for persons with dementia and spousal caregivers yet limited work has examined *both* partners' perceptions of challenges and coping after diagnosis. This qualitative study investigated the psychosocial stressors and adaptive coping strategies in couples diagnosed with YOD to inform the development of psychosocial support resources.

**Research Design and Methods:** We conducted live video dyadic interviews with couples (persons with YOD and spousal caregivers together;  $N = 23$  couples). We transcribed interviews and coded data based on a hybrid deductive–inductive approach, with the structure of the coding framework informed by the stress and coping framework, and all codes derived from the data. We derived themes and subthemes related to psychosocial stressors and adaptive coping.

**Results:** We identified 5 themes related to psychosocial stressors: the impact of diagnosis, social and family relationships, changing roles and responsibilities, planning for an uncertain future, and couple communication and relationship strain. We identified 7 themes related to adaptive coping strategies: processing emotions and cultivating acceptance, promoting normalcy, efforts to preserve persons with YOD's independence and identity, collaborative and open communication, social support, meaning-making, humor, and positivity, and lifestyle changes and self-care.

**Discussion and Implications:** We replicated several themes regarding stressors and adaptive coping strategies from prior YOD research and identified novel themes and subthemes related to dyadic stressors, sources of couples' relationship strain, and the ways in which couples effectively cope with YOD. Findings inform the development of dyadic interventions to reduce YOD-related distress for both persons with dementia and spousal caregivers.

**Keywords:** Coping, Couples, Dyads, Qualitative, Stressors, Young-onset dementia

Young-onset dementias (YODs) are characterized by symptoms that develop earlier in life, typically before age 65 (Ducharme & Dickerson, 2015). YODs often

have symptom profiles that are atypical compared to dementias diagnosed in later ages, including less frequent amnesia and more frequent mood, personality, and be-

havioral changes as well as language and communication deficits (Ducharme & Dickerson, 2015). At present, YOD is understudied and overlooked in medical settings given its perceived low prevalence, high rates of misdiagnosis, and atypical presentations (Bakker et al., 2013; Ducharme & Dickerson, 2015; Rosness et al., 2016). Persons with YOD also differ from older people with dementia in that they are often still employed, parenting or supporting children or older parents, and in otherwise good health at the time of symptom onset (Kelley et al., 2008).

Quantitative studies have shown that emotional distress is common in both persons with YOD and their informal caregivers—most commonly, spousal caregivers (Spreadbury & Kipps, 2019a). Emotional distress is triggered by challenges receiving an accurate diagnosis (Spreadbury & Kipps, 2019a, 2019b) and can be magnified after a diagnosis is made due to discrepancies between persons with YOD's and spousal caregivers' understanding of the illness, lack of adaptive coping strategies, poor prognosis, lack of impactful treatments, and limited age-appropriate psychosocial resources (Millenaar et al., 2016; Spreadbury & Kipps, 2019b).

Given the tremendous emotional impact of YOD and the continued experience of considerable psychosocial stressors after diagnosis, stress and coping frameworks (Biggs et al., 2017; Lazarus & Folkman, 1984) can be used to understand ways of facilitating positive adjustment for both persons with YOD and their loved ones. Stress and coping frameworks have been used in studies of typical onset dementia (Gilhooly et al., 2016), with *stressors* defined as situations perceived as challenging, threatening, or aversive and *coping strategies* as responses enacted to manage stressors (Biggs et al., 2017; Lazarus & Folkman, 1984). Dyadic stress and coping frameworks were developed in recognition of the largely interpersonal nature of stressful circumstances produced by medical conditions (Bodenmann et al., 2019; Falconier & Kuhn, 2019) and are supported by a wealth of empirical data indicating that stress and coping are interdependent between close partners (Cook & Kenny, 2016; Kenny, 2018). These approaches suggest that (a) a person's experience of stressors affects both themselves and their partner and (b) dyadic (i.e., person with YOD and spousal caregiver as a unit) coping strategies can mitigate the impact of such stressors. Though such frameworks have yet to be applied to YOD, a number of evidence-based dyadic (i.e., person with dementia and caregiver together) interventions have been developed using this framework to promote adaptive coping following the onset of medical conditions (Falconier & Kuhn, 2019; Moon & Adams, 2013; Van't Leven et al., 2013; Vranceanu et al., 2020), including later-onset dementia. Understanding the nuanced experiences of couples with YOD through qualitative investigations provides an opportunity to develop dyadic interventions for this population.

In a recent meta-synthesis of qualitative studies (Bannon et al., 2020), we identified intense negative emotions surrounding the diagnosis, experiences of immense loss and grief as a result of the diagnosis, and changes in social relationships as stressors experienced by both persons with YOD and their caregivers. In order to cope with these stressors, both persons with YOD and caregivers frequently engaged in maladaptive coping strategies (e.g., avoidance), although they described having awareness of adaptive (i.e., helpful) coping strategies (e.g., problem-solving, social support, gratitude, and optimism). The majority of studies described in our meta-synthesis included either caregivers or patients. Only three studies examined the experiences of both persons with YOD and their caregivers using dyadic interviews (Harding et al., 2018; Wawrziczny, Antoine et al., 2016; Wawrziczny, Pasquier et al., 2016). These studies have identified stressors shortly after diagnoses including negative emotions and uncertainty about disease progression, functional challenges, and loss of independence for persons with YOD and disruption in their social networks. In two studies, Wawrziczny et al. described negative coping strategies that couples used, including overprotection from spousal caregivers and avoidance of challenging conversations about the disease (Wawrziczny, Antoine et al., 2016; Wawrziczny, Pasquier et al., 2016). Despite these important findings, the studies are limited in terms of their characterization of how persons with YOD and their caregivers experience YOD together. First, they focus on how caregivers could assist the person with YOD, rather than on the caregivers' own experiences. Additionally, they only included the Posterior Cortical Atrophy subtype of YOD (Harding et al., 2018) and early-onset Alzheimer's (Wawrziczny, Antoine et al., 2016; Wawrziczny, Pasquier et al., 2016) rather than a variety of YOD diagnoses. Finally, these studies tended to focus on negative coping patterns among couples. Therefore, more research is needed to understand how couples (a) cope with stressors as a unit, (b) navigate a variety of YOD diagnoses, and (c) utilize adaptive coping strategies to manage YOD-related stressors. Information on ways dyads effectively respond to YOD-related challenges as a unit can help to inform the development of effective psychosocial interventions.

In hopes of facilitating the development of psychosocial interventions that address the needs of persons with YOD and their spousal caregivers simultaneously, we sought to build on prior research and comprehensively explore the experiences of couples coping with YOD. We used dyadic stress and coping frameworks (Bodenmann et al., 2019; Falconier & Kuhn, 2019) to guide our qualitative analyses, with the objective of gathering perspectives on (a) the psychosocial stressors faced by couples and (b) the adaptive coping strategies employed by couples after a YOD diagnosis. We chose to use dyadic interviews of persons with YOD and spousal caregivers together to characterize their experiences as a unit.

## Method

### Participants and Procedures

Our Institutional Review Board approved all study procedures. We used convenience sampling to recruit participants from our institution's dementia clinic as well as through social media pages for people living with YOD (e.g., Facebook). Interested and potentially eligible couples were contacted by the study staff for screening. We contacted 38 couples for screening. Four couples declined participation, with three declining due to time constraints and one declining due to the emotional nature of the interview. In addition, five couples were deemed ineligible, and six couples were unresponsive to the scheduling of a screening phone call. Couples were eligible for inclusion if (a) both partners were adults (18 or older), (b) both partners were English-speaking, (c) one partner had received a diagnosis of some form of YOD (e.g., forms of frontotemporal dementia or Alzheimer's disease), and (d) both partners were involved in a cohabitating romantic relationship at the time of study enrollment. Couples were excluded if (a) either the person with YOD or their spousal caregiver was unwilling to participate, or (b) the neurologist or neuropsychologists on the study team determined that the person with dementia's cognitive impairment was too severe to meaningfully participate in the interview. A total of  $N = 23$  couples met eligibility criteria and were enrolled in the study based on a target sample size of  $N = 20$  selected to feasibly facilitate thematic saturation (Boddy, 2016). Written informed consent was collected electronically for both persons with YOD and spousal caregivers. All couples participated in the study between January and August 2020.

After informed consent procedures, a research coordinator scheduled couples for 1-h interviews over Zoom, a secure telehealth platform. Interviews were scheduled to accommodate couples' preferences, taking into account times of day when persons with YOD were likely to be most alert and engaged. We chose to conduct interviews over live video to minimize barriers to participation (e.g., time, travel, and cost) and based on our prior work indicating that couples coping with neurological conditions found live video feasible and acceptable for participation (Vranceanu et al., 2020). If needed, a member of the study team (P. Popok) provided couples with assistance using Zoom and initiating the live video interview. Interviews were semistructured and conducted using a guide (see [Supplemental Materials](#)) that was informed by the dyadic stress and coping framework and iteratively developed by a multidisciplinary team that included a neurologist, a neuropsychologist, a speech-language pathologist, three clinical psychologists, and the spouse of a deceased person with YOD. Interviews were conducted by a clinical psychologist trained by the multidisciplinary team. Interviews began with a standardized introduction that encouraged both members of the couple to share their perspectives throughout the conversation, including differences in perspectives or experiences within

couples. Interview domains included (a) psychosocial stressors experienced since diagnosis and (b) strategies for coping with YOD-related stressors, consistent with the stress and coping theoretical framework (Biggs et al., 2017; Falconier & Kuhn, 2019; Lazarus & Folkman, 1984). Most interview questions were open-ended in nature. All study interviews were audio-recorded, transcribed, and deidentified (i.e., names of participants, locations, and names of others removed).

### Data Analysis

Our approach to thematic data analysis and interpretation utilized a hybrid of *deductive* and *inductive* coding techniques (Fereday & Muir-Cochrane, 2006). The structure of our coding framework was deductive in the sense that our team considered the stress and coping theoretical framework (Bodenmann et al., 2019; Falconier & Kuhn, 2019) during our review of transcripts, with the goal of characterizing both stressors and coping strategies. However, our approach was also inductive in the sense that all of our specific codes pertaining to the stressors and coping strategies reported by couples were generated from the data during the open coding of interview transcripts, rather than from prior literature. We derived all of our themes and subthemes from the coded data using inductive techniques based on the Framework Method procedures (Gale et al., 2013) to ensure rigor in the analysis in line with our desire to take a systematic approach. Given our overarching goal of generating findings related to persons with YOD's and spousal caregivers' experiences of psychosocial stressors and adaptive coping strategies as a unit, we adopted a primary focus on elucidating *couple-level* findings. We describe the processes in more detail below.

First, all recordings were manually transcribed verbatim by trained research assistants. We used a stepwise process that began with familiarization with data by the researchers. All members of the research team involved in the analysis process (S. Bannon, M. Reichman, P. Popok, M. Gates, V. Grunberg, A. Vranceanu) developed familiarity with the data through reading interview transcripts, listening to audio recordings, and discussing observations. We developed an initial analytical framework inductively by open (unrestricted) coding of four interview transcripts to identify preliminary codes (i.e., conceptual labels assigned to excerpts of raw data, such as "memory-related challenges"). In open-coding transcripts, we focused on codes that captured challenges or stressors described by interviewees, as well as codes that captured strategies to cope with challenges, consistent with the stress and coping framework (Biggs et al., 2017; Lazarus & Folkman, 1984). We then inductively organized codes into categories (i.e., clusters of codes around a similar concept that begins the process of abstraction of the data, such as "behavioral and cognitive challenges").

The analytical framework was systematically applied to the data set, which was coded independently in the NVivo 12 software package (QSR International, 2018) by two members of the research team (P. Popok, M. Reichman) before discussions to reach a consensus.

We took a collaborative and iterative approach to data interpretation, in which three team members (S. Bannon, M. Reichman, and P. Popok) looked at the charted data within each code, and identified findings relating to stressors and coping strategies across cases. Couple-level findings were identified based on a mutual discussion of the theme from both persons with YOD and spousal caregivers across couples, as well as partners' descriptions of the stressor or coping strategy using a "we" frame (i.e., "we" statements). Findings were clustered and discussed with the broader team to identify superordinate themes and subthemes. All themes and subthemes were iteratively revised in order to reduce redundancy in their articulation without loss of granularity. Of note, we allowed themes and subthemes to overlap (e.g., findings pertaining to couples' descriptions of changes in their household roles and findings pertaining to couples relationship changes) in order to preserve differences in experiences and opinions across couples. Furthermore, we sought to preserve overlapping findings in order to generate a complete picture of couples' varied lived experiences after YOD diagnosis.

## Results

### Sample Characteristics

See Table 1 for participant characteristics. Persons with YOD (11 females and 12 males) were 61.30 (standard deviation [SD] = 4.65) years old at the time of the dyadic interviews. Spousal caregivers (12 females and 10 males) were 60.52 (SD = 5.41). Couples were predominantly opposite sex (one same-sex couple) and had a relationship length of approximately 34 years on average (SD = 9.65). Persons with YOD were interviewed for approximately 3.11 years (SD = 3.85) since the initial onset of dementia symptoms, and more than half were diagnosed with Alzheimer's dementia. Couples had an average Clinical Dementia Rating Scale Score of 0.59 (SD = 0.44).

Thematic analysis of dyadic interviews revealed themes and subthemes pertaining to psychosocial stressors experienced and adaptive coping strategies enacted after a diagnosis of YOD. Couple-level themes, findings, and illustrative quotes related to psychosocial stressors are presented in Table 2, and themes, findings, and illustrative quotes related to coping strategies are presented in Table 3. Prominent subthemes are identified in the text in parentheses.

### Psychosocial Stressors

#### Theme 1: Impact of diagnosis

This theme encompasses four subthemes related to the primary ways in which couples were initially affected by

the YOD diagnosis (Table 2). Couples endorsed intense and complex emotions (e.g., sadness, depression, and loss; subtheme 1) and feeling "blindsided" by the diagnosis and its impact on their future together (subtheme 2). After diagnosis, many persons with YOD and spousal caregivers experienced a strong desire to identify a possible "cause" of the YOD and understand what to expect with regard to the prognosis (subtheme 3). However, the search for information was met with additional barriers. For example, one spousal caregiver mentioned: "I mean if we look at the website and whatnot, we know how the disease progresses ultimately, which is very sobering. But we don't have a sense where in the progress [person with YOD] is" (Dyad 13).

#### Theme 2: Social and family relationships

This theme includes four subthemes describing the impact of YOD on social and family relationships. Couples experienced stressors related to disclosing the diagnosis to friends and family members (subtheme 1). Specific challenges included navigating persons with YOD's avoidance and denial of YOD with friends and family and managing others' questions and emotional reactions in the midst of their own uncertainty. Notably, many symptoms of YOD (e.g., communication difficulties, disinhibition, and apathy) made it challenging for persons with dementia and spousal caregivers to maintain their relationships with family and friends (subtheme 3). Spousal caregivers also discussed difficulties determining when and how to help persons with YOD communicate and behave in social settings. Many described the experience of friends "disappearing," leading to increased isolation and loneliness for both partners (subtheme 3). As one person with YOD described: "What struck me about this whole journey was that I lost a lot of friends. I don't know if they were frightened, or they didn't want to have to see someone with Alzheimer's, or they didn't know what to do or something like that ... so that was a big thing" (Dyad 1). Couples with children faced additional unique challenges including (a) helping children cope with parental YOD diagnosis, (b) maintaining their parental roles despite illness, and (c) navigating concerns about the potential heritability of YOD (subtheme 4).

#### Theme 3: Changing roles and responsibilities

This theme encompasses five subthemes concerning the psychosocial stressors couples experienced related to changing roles and responsibilities within their spousal relationship. YOD's progressive symptoms led to changes in couples' typical daily routines and general lifestyle (subtheme 1), with increased roles/responsibilities for spousal caregivers and a loss of independence and roles/responsibilities for persons with YOD. As this shift took place, many couples found it difficult to navigate persons with YOD's changing abilities, including when to cease participating in specific activities (e.g., working, driving, and cooking; subtheme 2). Furthermore, many persons with YOD and spousal caregivers described feeling overwhelmed and frustrated in their communication about such changes. Couples

**Table 1.** Participant Characteristics (*N* = 23 couples)

Variables	Spousal caregivers	Persons with YOD
Sex, <i>n</i> (%)		
Female	13 (57)	11 (48)
Male	10 (43)	12 (52)
Race/ethnicity, <i>n</i> (%)		
White, not Hispanic or Latino	21 (91)	20 (87)
White, Hispanic or Latino	0 (0)	1 (4)
Asian, not Hispanic or Latino	1 (4)	0 (0)
More than one race, not Hispanic or Latino	0 (0)	1 (4)
Chose not to respond	1 (4)	1 (4)
Education, <i>n</i> (%)		
Completed high school or equivalent (12 years)	1 (4)	0 (0)
Some college/associates degree (<16 years)	2 (9)	4 (17)
Completed 4 years of college (16 years)	8 (35)	10 (43)
Graduate/professional degree (>16 years)	12 (52)	9 (39)
Relationship length, years		
Mean ( <i>SD</i> )	—	33.70 (9.65)
Range	—	13–48
Median	—	33
Age at interview, years		
Mean ( <i>SD</i> )	60.52 (5.41)	61.30 (4.65)
Range	49–69	54–70
Median	60	62
Age at symptom onset ( <i>n</i> = 19), years		
Mean ( <i>SD</i> )		56 (4.04)
Range		49–63
Median		56
Age diagnosed, years		
Mean ( <i>SD</i> )		57.87 (5.33)
Range		45–67
Median		59
Years since diagnosis at the time of interview, years		
Mean ( <i>SD</i> )		3.11 (3.85)
Range		0.17–17
Median		2
Diagnosis, <i>n</i> (%)		
Atypical AD		8 (35)
Typical AD		4 (17)
Language variant FTLD		2 (9)
Behavioral variant FTLD		4 (17)
Atypical FTLD		1 (4)
Prodromal FTLD		1 (4)
PSP		2 (9)
Unspecified early-onset dementia		1 (4)
Standard Global Clinical Dementia Rating Scale ( <i>n</i> = 17)		
Mean ( <i>SD</i> )		0.59 (0.44)
Range		0–2
Median		0.5

Note: AD = Alzheimer's disease; FTLD = frontotemporal lobar degeneration; PSP = progressive supranuclear palsy; YOD = young-onset dementia.

described losing the “easy way of making things work,” with their collective responsibilities, especially with changes that contradicted their longstanding relationship roles and division of responsibilities (subtheme 3). For example, as one spousal caregiver described, referring to taxes and

financial management: “I’m starting to have to take care of way more than I used to have to do and start taking care of the things that [person with YOD] always historically has done, and that’s stressful” (Dyad 2). Persons with YOD described experiencing negative emotions (e.g.,



**Table 2.** Couple-Level Psychosocial Stressors Observed in YOD Couples

Themes	Subthemes	Illustrative quotes
Theme 1: Impact of diagnosis	<ol style="list-style-type: none"> <li>1. Intense emotion (shock, sadness, depression) due to terminal diagnosis</li> <li>2. Feeling “Blindsided” by diagnosis in connection to ideas about future</li> <li>3. Quest to understand “cause” of YOD for an otherwise healthy person with YOD</li> <li>4. Impact affected by previous personal exposure to dementia (e.g., having served as a caregiver to parent with dementia)</li> </ol>	<p><i>It was cruel because we had no idea ... I went to work the next day and wept all the way to work—and I’m not a weeper—and I got to work, I opened the door, I shut the door and went back home again.</i> (Spousal caregiver 3)</p> <p><i>I was denying it a lot. I felt if I gave in too much, I just wouldn’t be worth it to anybody. I think I was trying to keep my persona alive.</i> (Person with YOD 1)</p>
Theme 2: Social and family relationships	<ol style="list-style-type: none"> <li>1. Challenges disclosing YOD (e.g., persons with YOD’s denial, fear of unanswerable questions, stigma, managing others’ emotions)</li> <li>2. Friends “disappearing,” loss of social support, and isolation</li> <li>3. Changes in couple social roles (e.g., spousal caregiver needing to talk more)</li> <li>4. Concern for children’s coping and well-being, as well as children’s risk due to possible genetic component of illness</li> </ol>	<p><i>Society is telling you, you are no longer a person, and you fit into this box. Neither of which are true.</i> (Person with YOD 15)</p> <p><i>A lot of our friends disappeared, they couldn’t handle it and disappeared.</i> (Spousal caregiver 11)</p> <p><i>I’m the one doing most of the talking. I was always relatively shy. [Person with YOD] was always the one that told the stories, he was always the dominant conversation when we were out for company, and he’s much quieter now.</i> (Spousal caregiver 3)</p>
Theme 3: Changing roles and responsibilities	<ol style="list-style-type: none"> <li>1. Emotional distress (e.g., confusion frustration, anxiety) due to person with YOD’s needs and responsibility shifts for both partners</li> <li>2. Difficulty navigating person with YOD’s safety with tasks (e.g., driving)</li> <li>3. Loss of “easy way of making things work” for tasks/hobbies</li> <li>4. Shift of chores (e.g., grocery shopping, bills) and personal care tasks of persons with YOD (e.g., shaving, dressing) to spousal caregiver</li> <li>5. Difficulty navigating responsibility shifts that contradict prior relationship roles/division of tasks (e.g., managing finances)</li> </ol>	<p><i>I simply tell her “I can’t do this. I need your help.” I’m sure it’s not wonderful for CG’s perspective. You know, not only do you lose somebody that you have a relationship with but suddenly you have to become more of a caretaker.</i> (Person with YOD 19)</p> <p><i>Being productive in a way that was contributing to the well-being of the family ... that got stripped away.</i> (Person with YOD 23)</p> <p><i>It’s a really hard job because essentially you take on the work of both people which was split evenly between our marriage.</i> (Spousal caregiver 17)</p>
Theme 4: Planning for an uncertain future	<ol style="list-style-type: none"> <li>1. Unmet desire to understand the timeline of YOD progression and “not knowing what the next day is gonna bring”</li> <li>2. Emotional/practical challenge of inevitable/unpredictable declines and preparing for “multiple possible futures at once”</li> <li>3. Financial hardship due to loss of persons with YOD and/or spousal caregiver ability to work</li> <li>4. “Jumping through hoops” to navigate legal, financial, and medical matters without guidance and with a sense of urgency</li> <li>5. Lack of age-appropriate or diagnosis-specific resources/support</li> </ol>	<p><i>It’s so uncertain, I mean we could have everything all planned out, and I mean he—it’s been a very slow, steady decline, but it could speed up. It could slow down; we just don’t know, so it’s really hard to plan ahead, so we’re really just kind of taking it day by day.</i> (Spousal caregiver 24)</p> <p><i>We don’t have a sense where in the progress [person with YOD] is and that has implications for decisions we need to make together. So that is probably top of mind for me is how trying to get a sense of how early in the evolution of the disease are we?</i> (Spousal caregiver 13)</p> <p><i>Frankly there is a lot of other preparation work in terms of the house and how we are set up and caregiving things, I just don’t know if that is 12 months away, or that’s 3 years away or 5 years away, we don’t really have a sense of that at all.</i> (Spousal caregiver 13)</p>

Table 2. Continued

Themes	Subthemes	Illustrative quotes
Theme 5: Couple communication and relationship strain	1. Individual denial/avoidance of certain topics (e.g., future progression) and emotional distress (e.g., feelings of guilt, burden, confusion, and fear of hurting partner) impedes effective communication	<i>Well, it was starting to get strained, I think, you know we're strong in our opinions in things, and I was just pushing back on [spousal caregiver]—“This isn't that bad, maybe just getting old or something like that.”</i> (Person with YOD 1)
	2. Person with YOD verbal/cognitive symptoms disrupt communication (e.g., word-finding difficulty, slower speaking, incomplete thoughts)	<i>I don't talk about it. I'm pretending it's gonna go away. But yeah I did get very very angry with him when I found out he told all my friends.</i> (Person with YOD 26)
	3. Narrow emotional capacity in person with YOD erodes depth of conversations	<i>Communication has probably been one of the biggest challenges. It's hard to have a conversation because of the speed of communication. I don't know if he's understanding my questions, so I usually have to repeat.</i> (Spousal caregiver 7)
	4. Mismatched coping strategies (e.g., denial vs. problem-solving)	<i>I think part of the walking on eggshells is the fact that he doesn't want to make decisions, but yet he wants to make the decisions, so that loss of control is a constant battle.</i> (Spousal caregiver 24)
	5. Disagreement over symptom severity, persons with YOD's abilities, shift of responsibilities, and disclosure of diagnosis to others	<i>Usually we can resolve conflicts by just talking, but at this point, I was seeing that his struggle was—you know, he was struggling one way to avoid and I'm struggling to problem-solve. We just kept kind of smashing into each other.</i> (Spousal caregiver 1)
	6. Differences in preferences for time together, energy levels, activity	
	7. Overprovision of spousal caregiver support	
	8. Relationship strain due to person with YOD cognitive and personality changes (e.g., forgetting conversations, loss of objects, irritability, obsessiveness, disinhibition, poor insight, low empathy), continuation/exacerbation of pre-YOD relationship problems	

Note: YOD = young-onset dementia; CG = caregiver.

frustration, blame, and anger) toward spousal caregivers at times, particularly when they perceived spousal caregivers as providing excessive support (i.e., overprovision) or acting “controlling.” In contrast, spousal caregivers shared that they experienced difficulty knowing when to provide support or assistance to persons with YOD, and a difficult transition from “a life based on two people with two people managing it together” to “a life based on two people with one person managing it alone” (Dyad 12).

#### Theme 4: Planning for an uncertain future

This theme encompasses five subthemes regarding challenges planning for the future after YOD diagnosis and the ways in which couples were affected by uncertainty in the expected symptom progression. Most couples interviewed described a strong, unmet need for more information pertaining to the expected progression of the diagnosis and the person with YOD's abilities (subtheme 1). The continual search for more information was described by one person with YOD: “Basically, medicine doesn't understand this thing well and so, we're looking for a level of clarity that doesn't exist” (Dyad 19). Both persons with dementia and spousal caregivers described being overwhelmed by the uncertainty

of when declines would occur and that a “step downward is not a ramp ... it is a step down hard, and sometimes it's a big step” (Dyad 25; subtheme 2). Couples felt overwhelmed and frustrated attempting to plan for “multiple futures all at once,” and one couple described their experience as developing “a new plan and then that would get blown up and we would develop a different plan, and then that would get blown up” (Dyad 11). Many experienced unexpected financial hardships following the loss of work-related income and described “jumping through hoops” to navigate legal, financial, and medical matters with minimal support or resources, as well as a general lack of age-appropriate resources for YOD (subtheme 3).

#### Theme 5: Couple communication and relationship strain

This theme encompasses eight subthemes that identified a number of sources of communication disruptions and relationship strain, which varied within couples over time and across couples based on the YOD diagnosis and the couples' relationship functioning. Couples described mutual avoidance of certain topics, including plans for the progression of symptoms and future care needs (subtheme 1). In addition, couples shared that their ways of communicating

**Table 3.** Couple-Level Adaptive Coping Strategies Observed in YOD Couples

Theme	Subthemes	Illustrative quotes
Theme 1: Processing emotions and cultivating acceptance	1. Normalizing frustration and anger for both partners; partners balancing each other when one is experiencing emotional distress	<i>It was devastating, and we gathered our kids together and told them personally and said okay, we've got to make a plan for the rest of our life.</i> (Spousal caregiver 19)
	2. Focusing on the present moment and current challenges to minimize emotional distress (e.g., anxiety, fear/worry, loss)	
Theme 2: Promoting normalcy	1. Finding a "new normal" through grieving and accepting what is lost	<i>Your life is now different so how do you deal with the way it is now, not the way it used to be, but grieve what you lost, but move forward with what you have.</i> (Spousal caregiver 11) <i>I have to always remind myself that the plan may not work the way I need it to work so I have to have a Plan B. You have to have multiple scenarios. So as long as you have multiple scenarios I am okay.</i> (Spousal caregiver 12) <i>Yeah I mean I think because she's so functional, we don't dwell on limitations, and we don't really look to a future that is dark or think about a dark future.</i> (Spousal caregiver 10) <i>I just kind of say "we're going to get you through it." I mean it happens. I have a bad day, but we kind of just move on from it. Don't want to be stuck in it because if I did, I'd just sometimes feel worse than I do at the moment, you know.</i> (Spousal caregiver 16)
	2. Mutual "unafraid and accepting" stance, including with role changes	
	3. Flexibility with future plans (e.g., Plan B, Plan C)	
	4. "Not dwelling"—not thinking about upsetting topics to avoid getting stuck in intense negative emotions	
	5. Taking things "day-by-day," focus on what has not changed and find ways to "do the regular things together"	
	6. Reframing problematic behaviors of persons with YOD as how a person with YOD has always been (e.g., outspoken, reactive) to promote identity continuity	
	7. Mutual avoidance of upsetting topics (e.g., fact that person with YOD is ill, person with YOD's limitations, bad days, uncertainty of future)	
Theme 3: Efforts to preserve person with YOD independence and identity	1. Adopting problem-solving attitude; taking challenges in stride	<i>When I'm home cooking dinners, I try to give [person with YOD] specific tasks, where I know she can access something.</i> (Spousal caregiver 5) <i>[Person with YOD] is probably the most positive person I've ever known. And just doesn't let it get her down, just keeps going. There are some big challenges like [person with YOD is] at a place now where she struggles to get dressed every day in the morning, although she perseveres and will not stop.</i> (Spousal caregiver 5)
	2. Spousal caregiver finding ways to help persons with YOD with deficits (e.g., writing step-by-step instructions about daily tasks, detailed notes, or pictures)	
	3. Working together to preserve persons with YOD's contributions in daily activities	
	4. Attention to targeted support for persons with YOD in completing daily tasks (e.g., persons with YOD can dress and groom, but needs help picking outfit)	
Theme 4: Collaborative and open communication	1. Open communication about symptoms, medical care, end-of-life preferences, emotions, needs and desires, and responsibility shifts	<i>Every time I don't remember something, I ask my wife. That really helps my memory a little bit too because the words I get back, sometimes will remember them.</i> (Person with YOD 14) <i>[Person with YOD is] not afraid to die. And she's had discussions with all of the children about that.</i> (Spousal caregiver 17) <i>Every time there's an incident we try to sit down and talk it through and try to get each other's perspective and try to talk about what would make it better the next time. We both get frustrated ... and there's not a lot we can do every time except deal with it afterwards.</i> (Spousal caregiver 2)
	2. Collaborative planning for future to shift focus to present moment	
	3. Planning conversations for when both people are in best "frame of mind" (e.g., walks, date nights, dinners)	
	4. Willingness to pause conversations; apologizing for losing patience	
	5. Problem-solving communication barriers (e.g., discussing when it is helpful for the spousal caregiver to help with word-finding/sentence completion)	



Table 3. Continued

Theme	Subthemes	Illustrative quotes
Theme 5: Social support	<ol style="list-style-type: none"> <li>1. Openness with social network about YOD and problem-solving barriers to disclosure (e.g., utilizing a script)</li> <li>2. Educating friends/family about YOD to combat stigma, promote understanding, and provide strategies for interacting with persons with YOD</li> <li>3. Maintaining friendships and staying in touch with friends</li> <li>4. Meaningfully engaging in social support network of individuals with similar lived experiences (e.g., local Alzheimer's Association, Facebook groups)</li> <li>5. Accepting practical/tangible support from the existing social network (e.g., groceries, legal advice)</li> <li>6. Spirituality/religious participation—either through prayer or involvement in a church organization</li> </ol>	<p><i>We got involved with the association, we found a bit of a network you might say, of people locally that were all in the same path.</i> (Spousal caregiver 15)</p> <p><i>We have a lot of good friends ... And they're our support group along with our daughters so you know having support people that can help out is good.</i> (Spousal caregiver 26)</p>
Theme 6: Meaning-making, humor, and positivity	<ol style="list-style-type: none"> <li>1. Reframing dependency as positive couple intertwinement</li> <li>2. Gratitude for persons with YOD's present identity and abilities</li> <li>3. Appreciation for relationship and quality time (e.g., walks, trips, drives, reading, conversations)</li> <li>4. Reorienting priorities for remaining time; prioritizing time together and special experiences with family (e.g., dates/vacations)</li> <li>5. Using humor to confront daily challenges/difficult conversations</li> </ol>	<p><i>I rely on [person with YOD] a lot for judgement and things with our daughter ... decision making. She has wonderful insight. Despite dementia, she's still got so much to offer.</i> (Spousal caregiver 10)</p> <p><i>[Person with YOD] really enjoyed reading to our neighbor. It gave her so much positive energy and sense of self ... a way for her to feel useful instead of just being discarded.</i> (Spousal caregiver 10)</p> <p><i>We have participated in research and that is because we want to be helpful. We want to do anything we can that may be helpful to other people.</i> (Spousal caregiver 11)</p>
Theme 7: Lifestyle changes and self-care	<ol style="list-style-type: none"> <li>1. Emphasis on active lifestyle and finding "physical outlets" for stress (e.g., walking, sports, home renovations)</li> <li>2. Personal self-care routine/emphasis on mindfulness/relaxation</li> <li>3. Lifestyle changes to promote health (e.g., nutrition, exercise, minimizing alcohol consumption)</li> </ol>	<p><i>Nothing like ripping down walls and ceilings to channel your stress ... [person with YOD] has gone and focused his energy into his sports, whether its skiing or golf he pretty much does it every day. For me ... I bought this shack and I have been ripping it down and recapping that has been my outlet.</i> (Spousal caregiver 4)</p>

Note: YOD = young-onset dementia.

with each other were challenged by verbal and cognitive YOD symptoms (e.g., word-finding difficulty, memory impairments, difficulty finishing thoughts/sentences; subtheme 2). The high-level nature of conversations had also diminished among couples, as many spousal caregivers reported having simple conversations without much depth with persons with YOD (subtheme 3). Partners shared that their own complex emotions (e.g., guilt, burden, confusion, fear of hurting their partner) were often difficult to discuss and served as barriers to having important conversations. These barriers exacerbated partners' differing perceptions of the person with YOD's symptoms and capabilities and prevented couples from coping with challenges as a team (subtheme 4). Many spousal caregivers described "walking on eggshells" with their partners, which contributed to a loss of intimacy and buildup of tension over time. In response, many spousal caregivers described painful moments of losing patience with their partner: "I was glad our girls couldn't hear upstairs because I unleashed on him like I have never unleashed on him. I was hysterically

crying, I was screaming. I was pretty much done. He felt terrible, and he got emotional too" (Dyad 23).

## Adaptive Coping Strategies

### Theme 1: Processing emotions and cultivating acceptance

This theme contains two subthemes pertaining to the strategies that couples identified to cope with challenging emotions and cultivate acceptance of the YOD diagnosis. Many couples found it helpful to work toward acknowledging and accepting difficult emotions (e.g., sadness, fear, shame, and frustration) and discussing their individual emotional experiences together (subtheme 1). Persons with YOD and spousal caregivers also discussed allowing themselves to grieve the losses associated with YOD (e.g., loss of expected future, identities). By acknowledging such losses, couples were more accepting of shifting roles and responsibilities and could better navigate challenges as a team. As one spousal caregiver described:

“We’re still gonna be a married couple who care about each other deeply. [YOD] wasn’t gonna change that stuff, you know. Somethings were gonna have to change. I was gonna have to do things that we always did together. I was going to have to do them alone. I’m gonna have to be more patient. You know, that kind of stuff, but it was doable. I felt like—phew—it’s doable, we can make this work. It sucks, but we can make it work” (Dyad 1). In the midst of challenging emotions, couples found it helpful to adopt a present moment focus (subtheme 2).

### **Theme 2: Promoting normalcy**

This theme encompasses seven subthemes concerning the variety of strategies that couples undertook to minimize the impact of the YOD diagnosis on their day-to-day life and preserve a sense of normalcy. To manage negative emotions, persons with YOD and spousal caregivers both emphasized the importance of “not dwelling” on declines in persons with YOD and worries about the future (subtheme 4). Often, one partner was better at “not dwelling” than the other, which frequently was persons with YOD because of their reduced insight and emotional range. As one spousal caregiver described: “There’s also things that should spark a response [in person with YOD] and there’s a detachment there. Both of us have always been very practical people and not really want to talk about things ’cause you know talking doesn’t really do anything. There’s no emotional reaction. What can you do?” (Dyad 26). Couples found it helpful to take things day by day, focus on the unchanged aspects of their lives, and find ways to promote routines (subtheme 5).

### **Theme 3: Efforts to preserve person with YOD’s independence and identity**

This theme includes four subthemes regarding couples’ various ways of preserving the person with YOD’s identity and independence after a YOD diagnosis. Many couples highlighted the benefits of promoting the person with YOD’s independence in daily tasks and preserving their roles and responsibilities (subtheme 3). With these goals in mind, couples described having ongoing discussions about spousal caregiver’s support of the person with YOD’s completion of tasks, ways of working together in daily activities, and modifying the frequency and intensity of spousal caregivers’ support in daily tasks to preserve the person with YOD’s independence (subtheme 4). As one spousal caregiver described: “In the kitchen, I will try to help her get involved, to set the table, we empty the dishwasher, put the dishes away. Although, she no longer knows how to put the dishes away the same way they’ve been the past 20 years, so sometimes I’ll have to go back and reorganize” (Dyad 8). This effort by spousal caregivers to involve their partner was received positively by the partner with YOD, for example, this spousal caregiver’s partner (Dyad 8) responded: “Yeah. In the house, or when we’re going somewhere ... I want to share, share together.”

### **Theme 4: Collaborative and open communication**

This theme contains five subthemes that include the strategies that couples identified were useful for facilitating open communication about the stressors they experienced individually and as a unit after YOD diagnosis. Couples highlighted the benefits of open communication, especially in challenging circumstances (e.g., difficult emotions, changing roles and responsibilities, and behavioral and communication disruptions produced by YOD; subtheme 1). Couples identified strategies to facilitate open and effective communication, which included collaboratively planning for the future (subtheme 2) and planning conversations when both partners were in the best “frame of mind,” intentionally creating space for conversation (e.g., date nights, walks; subtheme 3), and being willing to pause conversations that are emotionally overwhelming (subtheme 4). Couples described their conversations as ongoing, with both partners being willing to pause, repeat, and continue discussions over time, sometimes with a sense of levity and humor. As one person with YOD joked, “And sometimes I’ll forget that so ... we have to [have the conversation] again” (Dyad 2). Finally, couples discussed problem-solving conversational barriers in order to promote effective communication (subtheme 5).

### **Theme 5: Social support**

This theme concerns six subthemes that describe ways in which couples meaningfully engaged in social support and navigated potential disruptions to their social network in the context of YOD. Persons with YOD and spousal caregivers discussed the benefits of open communication with family and friends (subtheme 1). Couples identified tools to educate their social network about YOD to combat stigma and promote communication, such as using scripts or cards with important information about the person with YOD’s condition and symptoms (subtheme 2). Spousal caregivers also often urged persons with YOD to disclose the diagnosis to close friends and families, as a way for others to gain insight into personality and behavior changes. Often, persons with YOD had to reach a level of acceptance before disclosing, which spousal caregivers could assist with. In the midst of losing friends after diagnosis, couples described a heightened importance to staying connected to their social networks, and feelings of appreciation for friends who kept in touch, either stopping by to visit or calling regularly to check-in (subtheme 3). As one spousal caregiver described: “A very dear friend [of a person with YOD] came over twice a week. They watched everything they could watch on Netflix together. After that girl time stuff so they have two or three hours out there yacking it up, and I get a bunch of work done doing some of my own work” (Dyad 17). Couples also described the benefits of building a support network of individuals with similar experiences (subtheme 4), as well as the larger benefits of community involvement (subtheme 6).

### Theme 6: Meaning-making, humor, and positivity

This theme encompasses five subthemes related to the ways in which couples learned to find a balance between the myriad challenges after YOD diagnosis by shifting their priorities to cultivate positive and enriching experiences. After the diagnosis, many couples reoriented their routines and priorities to cultivate positivity, gratitude, and appreciation and to make the most of their time together and with friends, family, and others in the YOD community (subtheme 1). For example, one spousal caregiver described: “You know, last year, we couldn’t have gone on a vacation it would’ve been too hard. And then, one day, [person with YOD] said, We gotta go on a vacation in two weeks ... We have friends who have house who want us ... And we got all the kids together ... and we had ... a 5-day vacation away” (Dyad 17). Many couples used humor as a way of coping with daily challenges, reducing discomfort during difficult conversations, and to resolve disagreements. As one spousal caregiver described: “[Person with YOD] and I have sort of evolved a dark humor to talk about things. So we have Alzheimer’s jokes flowing around the place now” (Dyad 10). Their use of humor was part of a broader effort to reframe challenges in a positive light, which included expressing gratitude for the person with YOD’s intact abilities, increased time together, and the couple’s ability to work as a team (subtheme 2).

### Theme 7: Lifestyle changes and self-care

This theme contains three subthemes identifying strategies that couples enacted to promote a healthy lifestyle and engage in self-care strategies. Couples emphasized the benefits of healthy behaviors such as nutritional diet, regular movement/exercise, and mindfulness/relaxation techniques for managing stress, coping with daily challenges, and maintaining a routine (subthemes 1–3). As one person with YOD described: “I’m trying to make change in my lifestyle—I’m not drinking because they said that’s a trigger, that’s not a good thing. And we’re trying to eat healthy, as healthy as we can” (Dyad 26).

## Discussion

We used dyadic stress and coping frameworks to explore the psychosocial stressors and adaptive coping strategies experienced by couples after a YOD diagnosis. By including couples with a variety of YOD diagnoses, capturing couples’ experiences as a unit, using a theoretical dyadic stress and coping framework, and inquiring about adaptive coping, our study extends the findings of prior explorations of dyadic dynamics in couples after a YOD diagnosis (Harding et al., 2018; Wawrziczny, Antoine et al., 2016; Wawrziczny, Pasquier et al., 2016). Our findings provide invaluable information that can be used to develop future psychosocial interventions for couples navigating YOD. Our study identified couples’ psychosocial stressors that replicate those characterized in systematic reviews of persons

with YOD and their caregivers, including disruptions in couple communication, increased relationship strain, and difficulties navigating symptoms and planning for the future (Bannon et al., 2020; Harding et al., 2018). In line with previous literature (Harding et al., 2018; Wawrziczny, Antoine et al., 2016; Wawrziczny, Pasquier et al., 2016), we observed that couples described enacting adaptive coping strategies such as acceptance, social support, cultivating gratitude and optimism, and problem-solving to cope with the stressors they experienced after diagnosis. We also identified novel findings concerning couples’ relationship functioning that we describe in further detail below.

### Psychosocial Stressors

We identified novel subthemes that characterize the stressors surrounding the sources of increased relationship strain, including couples’ loss of familiar interactions, depth in daily conversations, and sense of intimacy and bond. Additionally, couples faced difficulties navigating responsibility shifts to compensate for persons with YOD’s limitations, particularly when the shifts contradicted with prior longstanding relationship roles and division of responsibilities. Many couples also discussed the negative impact of mismatched individual emotional experiences in connection to their ability to collaboratively plan for an uncertain future. Of note, our findings parallel those identified in systematic reviews of couples coping with dementias diagnosed in older ages, which describe relationship strain stemming from communication disruptions, role transitions, and mismatched individual experiences after diagnosis (Holdsworth & McCabe, 2018).

### Adaptive Coping Strategies

Our study revealed novel subthemes regarding the individual and dyadic coping strategies that couples enacted to promote effective communication, adjustment to new roles, and maintenance of identities. Couples made efforts to promote normalcy and emphasized the importance of “not dwelling” on stressors. In addition, many described the gradual process of learning to process difficult emotions and discussing challenging topics. Though they tended to avoid upsetting topics to manage overwhelming emotions, couples agreed that avoidance prevented them from working together to effectively cope with stressors and ultimately prolonged emotional distress. In order to facilitate collaborative and productive discussions, couples emphasized the importance of planning for conversations and viewing conversations as an ongoing process. Finally, couples discussed their process of navigating YOD symptoms and described the benefits of having detailed discussions about when persons with YOD would like assistance to promote the person with YOD’s independence. While these findings are novel in YOD, they are similar to those observed across qualitative studies of dyads coping with

older-onset dementias, which emphasize the importance of both partners opting for dyadic-oriented goals (e.g., shared interpretation and response to stressors) and behaviors that promote positive interactions (e.g., open communication about difficult emotions and topics, using humor as a buffer against stressors; [Bosco et al., 2019](#); [Hickman et al., 2020](#)).

### Clinical Implications

Rapid advances in biomarker research are now enabling clinicians to make more confident YOD diagnoses earlier in the course of the illness, when persons with YOD have fewer symptoms including a lesser degree of cognitive impairment ([Ducharme & Dickerson, 2015](#)). Along with these advances comes the opportunity to meaningfully engage persons with YOD in interventions with their caregivers and provide them with education and skills practice to promote adaptive coping in the midst of YOD-related challenges and progressive symptoms. Dyadic interventions that include both persons with neurological conditions and their informal caregivers have been successful in reducing emotional distress and improving quality of life across medical populations ([Pucciarelli et al., 2021](#); [Vranceanu et al., 2020](#)) including for later-onset dementias ([Moon & Adams, 2013](#); [Poon, 2019](#)). However, to date, there are no dyadic interventions for the person with YOD and their spousal caregiver, and dyads with YOD report a dissatisfaction with services geared toward those with older-onset dementias ([Spreadbury & Kipps, 2019b](#)).

Our qualitative study along with the body of qualitative and quantitative research provides support for dyadic interventions designed to promote resiliency after YOD diagnoses. Such interventions should address factors that contribute to emotional distress such as negative thought processes and rumination (“not dwelling”) and should improve adaptive coping by promoting independence and values (e.g., identity and role continuity, normalcy, quality time), and adjusting communication styles (e.g., open communication, skills to facilitate difficult conversations). For couples, skills such as collaborative problem-solving, cognitive strategies to manage overwhelming thoughts and emotions (e.g., acceptance, cognitive restructuring), values exploration, and interpersonal effectiveness may be useful to facilitate effective conversations and guide decision making after diagnosis. Given the parallels observed between our study and studies of older-onset dementias, it is possible that dyadic programs developed for older-onset dementias could be tailored to the unique stressors experienced by couples with YOD. Finally, the nuanced content of stressors and coping strategies across couples underscores the importance of tailoring interventions to meet couples’ specific needs after diagnosis.

### Limitations

We conducted interviews of persons with YOD and their spousal caregivers together based on our overarching goal

of informing the development of a dyadic intervention following a YOD diagnosis. All of the persons with YOD participated in the discussions, which allowed us to obtain perspectives from both partners simultaneously. While this can be conceptualized as a strength, it is also a weakness, as partners may not have shared as openly, frequently, or directly with the interviewer as they would have if interviewed alone. Furthermore, we chose to analyze data at the couple level in order to characterize couples’ shared experiences and allowed for overlapping themes and subthemes in order to fully capture findings reported across couples. While this decision can be viewed as a strength of our study, our study did not fully capture individual partners’ experiences, nor did we distinguish between experiences that were predominantly individual from those predominantly experienced by the couple as a unit. Given that our sample of couples was predominantly White and opposite sex, findings may not reflect perspectives of diverse persons with YOD and their spouses. Furthermore, our study focused on characterizing couples’ experiences after YOD diagnosis, and findings may not generalize to other dyads (i.e., parental, sibling).

### Future Directions

Future studies should continue this line of work and explore couples’ interest in participating in dyadic resiliency programs, as well as their perception of potential content, best delivery modality, and best time to implement the intervention. While an intervention delivered as early as possible after diagnosis may be most effective and efficient, some patients may still have cognitive symptoms that prevent them from meaningfully engaging in dyadic interventions. Such programs should seek to address unique barriers and tailor skills that promote adjustment to new normal, intimacy, and communication to promote couples’ well-being. An understanding of specific dyadic characteristics (e.g., relationship functioning of the couple, persons with YOD’s cognitive abilities) that are conducive to dyadic versus caregiver-only interventions will be also an important area for future research.

### Conclusions

In this study, we examined couples’ experiences following a diagnosis of YOD. To the best of our knowledge, our study was the first to use a dyadic stress and coping theoretical framework to obtain nuanced information on the psychosocial stressors and adaptive coping strategies the couples faced and enacted together, with the goal of informing dyadic psychosocial interventions. Using dyadic interviews, we identified *couple*-level themes pertaining to the experiences of persons with YOD and spousal caregivers as a unit. Our results illustrate the many complex psychosocial stressors that are experienced by both partners after diagnosis and adaptive coping strategies that persons with YOD and spousal



caregivers enact together to help manage such stressors. Our study is one of the first to employ a dyadic approach to gather more nuanced information on couples' experiences with YOD and extends the current literature by highlighting the shared stressors and coping strategies of couples facing YOD from the couple's perspective. This work lays the foundation for specialized psychosocial dyadic interventions that can facilitate adaptive coping for couples with YOD.

## Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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## Conflict of Interest

A.-M. Vranceanu reports serving on the Scientific Advisory Board for the Calm application outside of the submitted work. She also reports research support from the National Institutes of Health (NIH), NF-Midwest, NF-Texas, NF-Northeast, and royalties from Oxford University Press. B. C. Dickerson reports research support from NIH, Alzheimer's Drug Discovery Foundation, consulting for Acadia, Arkuda, Axovant, Lilly, Biogen, Merck, Novartis, Wave LifeSciences, editorial duties with payment for Elsevier (Neuroimage: Clinical and Cortex), and royalties from Oxford University Press and Cambridge University Press. All other authors declare no conflicts of interest.

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