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Review Article

In It Together: A Qualitative Meta-Synthesis of Common and Unique Psychosocial Stressors and Adaptive Coping Strategies of Persons With Young-Onset Dementia and Their Caregivers

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Abstract

Background and Objectives: The common and unique psychosocial stressors and adaptive coping strategies of people with young-onset dementia (PWDs) and their caregivers (CGs) are poorly understood. This meta-synthesis used the stress and coping framework to integrate and organize qualitative data on the common and unique psychosocial stressors and adaptive coping strategies employed by PWDs and CGs after a diagnosis of young-onset dementia (YOD).

Research Design and Methods: Five electronic databases were searched for qualitative articles from inception to January 2020. Qualitative data were extracted from included articles and synthesized across articles using taxonomic analysis.

Results: A total of 486 articles were obtained through the database and hand searches, and 322 articles were screened after the removal of duplicates. Sixty studies met eligibility criteria and are included in this meta-synthesis. Four themes emerged through meta-synthesis: (a) common psychosocial stressors experienced by both PWDs and CGs, (b) unique psychosocial stressors experienced by either PWDs or CGs, (c) common adaptive coping strategies employed by both PWDs and CGs, and (d) unique adaptive coping strategies employed by either PWDs or CGs. Within each meta-synthesis theme, subthemes pertaining to PWDs, CGs, and dyads (i.e., PWD and CG as a unit) emerged.

Discussion and Implications: The majority of stressors and adaptive coping strategies of PWDs and CGs were common, supporting the use of dyadic frameworks to understand the YOD experience. Findings directly inform the development of resiliency skills interventions to promote adaptive coping in the face of a YOD diagnosis for both PWDs and CGs.

Keywords: Caregiving, Dyads, Early-onset dementia, Stress and coping, Systematic review

Patients with a young-onset dementia (YOD)—defined by an age of onset younger than 65 years—commonly have atypical symptom profiles compared to late-onset dementia, including less frequent amnesia and more frequent executive dysfunction, aphasia, agnosia, mood and behavioral symptoms (e.g., personality changes, disinhibition, apathy), and sensorimotor symptoms as the illness progresses (Ducharme & Dickerson, 2015). Syndromic diagnoses in YOD include behavioral variant frontotemporal dementia (FTD), primary progressive aphasia, posterior cortical atrophy (PCA), and progressive dysexecutive syndromes (Bang et al., 2015; Mendez, 2019; Sapolsky et al., 2011; Wong et al., 2019). The etiologies of YOD include frontotemporal lobar degeneration, Alzheimer's disease, Lewy body disease, other neurodegenerative diseases, and other uncommon neurologic diseases.

In part because the diseases-causing dementia are relatively rare in people younger than 65, the diagnostic journey is long and filled with uncertainty and distress. The YOD diagnosis serves as a serious and life-altering event for both persons with YOD (PWDs) and their informal caregivers (CGs) (Spreadbury & Kipps, 2019b). In addition to the lack of cure and impactful treatments, YOD strikes people in the prime of their lives, when most are still working, raising children, and are free from other health conditions. Quantitative systematic reviews indicate that emotional distress is common in CGs and many PWDs after diagnosis. Qualitative studies characterize the nuanced experiences of PWDs and CGs after diagnosis, including the psychosocial stressors faced such as functional limitations of PWDs, increased PWD dependency on CGs, disruptions in the PWD–CG relationship and their larger social support network structure, social isolation, and stigma (Spreadbury & Kipps, 2019b). In the setting of YOD, PWDs and CGs face a shortage of age-appropriate psychosocial resources to facilitate adaptive coping and to prevent emotional distress and CG burnout (Millenaar et al., 2016).

Quantitative studies focused primarily on CGs have shown that PWD and CG emotional distress and high CG burden are a function of avoidant coping strategies (Spreadbury & Kipps, 2019a). Several qualitative studies have described the ways in which PWDs and CGs engage in avoidant coping strategies in order to sidestep difficult conversations and challenging emotions and attempt to preserve normalcy in their lives. Some of these strategies include avoiding social contact and minimizing or hiding their diagnosis (Greenwood & Smith, 2016). These strategies may provide initial relief and protection from intense emotions, but can lead to isolation and disconnection between PWDs, CGs, and their larger social network. In contrast, some PWDs and CGs describe using more adaptive coping strategies, including accepting changing abilities, finding humor in their situation, focusing on meaningful activities and positive experiences, and finding new ways to connect with others (Clemerson et al., 2014). However, the high rates of emotional distress and CG burden across quantitative studies (Spreadbury & Kipps, 2019a) suggest that few PWDs and CGs are able to consistently and effectively engage in adaptive coping strategies.

The stress and coping framework (Biggs et al., 2017; Lazarus & Folkman, 1984) provides a context for organizing and understanding the experiences of PWDs and CGs when faced with YOD. Within this framework, *stressors* are situations perceived as challenging, threatening, or aversive, and *coping strategies* are the responses persons adopt to manage these stressors (Biggs et al., 2017). Adaptive coping strategies buffer the effect of stressors and lead to good emotional health and quality of life. Because serious medical illnesses like YOD profoundly impact both persons with the diagnosis and their primary CGs, stress and coping frameworks expanded to focus on the dyad (i.e., PWD and CG as a unit; Falconier & Kuhn, 2019). Consistent with dyadic stress and coping models, an individual's stress and coping can impact not only their own emotional health, but also that of their partner. Within dyadic frameworks, both individual and dyadic coping strategies (i.e., PWD and CG enacted together) can mitigate the impact of stressors. Though a dyadic stress and coping framework has yet to be applied to the context of YOD, it could be used to understand (a) the stressors that PWDs and CGs experience individually and as a dyad, and (b) the adaptive coping strategies that PWDs and CGs can employ both individually and as a dyad to navigate the YOD diagnosis and associated challenges (Falconier & Kuhn, 2019).

With earlier and more confident diagnoses of YOD (Mayrhofer, Shora, et al., 2020) comes an important opportunity to engage dyads of PWDs and CGs in programs focused on teaching adaptive coping strategies. A necessary first step in developing such preventive dyadic interventions is to synthesize the qualitative literature on postdiagnosis psychosocial stressors and adaptive coping strategies of PWDs, CGs, and dyads. The question driving the present meta-synthesis is: What are the *common* (i.e., reported by both PWDs and CGs) and *unique* (i.e., specific to PWDs or CGs) psychosocial stressors and adaptive coping strategies of PWDs and their CGs after YOD diagnosis?

Method

Aim

We aimed to identify and synthesize qualitative studies examining the experiences of PWDs, CGs, and dyads in order to gain a deeper understanding of the stressors and adaptive coping strategies employed by each and to summarize the common and unique facets of their experiences to inform psychosocial resources for dyads of PWDs and CGs.

Search Strategy and Screening

Our meta-synthesis conforms with PRISMA guidelines (Moher et al., 2009), and is registered on PROSPERO

(CRD42020164802). We searched five electronic databases (PubMed, PsychINFO, CINAHL, MEDLINE, and Scopus) from inception until January 2020. The search strategy comprised three key concepts derived from our overarching aim: YOD diagnosis, qualitative research, and PWD or CG experiences (Supplementary Table 1). We used a three-stage screening approach to article selection, in which we (a) screened article titles for relevance, (b) applied inclusion and exclusion criteria (Table 1) to abstracts and full-text articles, and (c) discussed inclusion of articles among the study team where disagreement occurred between two reviewers. A detailed description of the search and screening procedure can be found in the Supplementary Materials.

Quality Appraisal

We assessed the methodological and reporting quality of all included studies using the 10-item Critical Appraisal Skills Program (CASP) (Critical Skills Appraisal Programme, 2018) The CASP comprises 10 criteria related to methodological and reporting quality of qualitative studies, including (a) clarity and appropriateness of objective and aims, (b) appropriateness of qualitative methodology, (c) study design, (d) sampling method, (e) data collection, (f) reflexivity of researchers, (g) ethics, (h) data analysis, (i) rigor of findings, and (j) significance of the research. Each criterion is rated using a three-category scale of No (1 point), Can't tell (2 points), and Yes (3 points), resulting in summed overall quality scores for each article ranging from 10 to 30. Two independent reviewers rated every included article and met to discuss disagreements in quality ratings to reach consensus. Overall, included studies were of good quality ($M = 25.75$; range = 19–30). Table 2 depicts the overall distribution of quality ratings for all criteria appraised.

Table 1. Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
1. Article is written in English	1. Article does not concern primary data collection (e.g., opinion article or literature)
2. Published in a peer-reviewed academic journal	2. Used quantitative methodology only for data collection and analysis
3. Concerns original research and primary data collection	3. Concerns patients or informal caregivers to patients with a diagnosis of later-onset dementia (patients aged 65 and older) or a non-YOD diagnosis
4. Used any type of qualitative methods for data collection or qualitative analysis of data (including mixed-methods)	4. Not relevant to the experiences, challenges, needs, or coping strategies of patients and/or caregivers, or concerning the pre-diagnosis period
5. Concerns patients or informal caregivers to patients with a diagnosis of YOD (patients aged 65 and under)	
6. Relevant to the experiences, challenges, needs, or coping strategies of patients and/or caregivers in the postdiagnosis period	

Note: YOD = young-onset dementia.

Data Extraction Process

Two reviewers read the full text of every article included in the analysis, and independently extracted findings within predefined domains of interest based on our research questions (i.e., (a) psychosocial stressors and (b) adaptive coping strategies, as relevant for (a) PWDs, (b) CGs, and (c) within the dyadic PWD–CG relationship). The two reviewers discussed discrepancies to reach agreement and consolidate findings.

Data Synthesis

We carried out data analysis using the analytical framework of meta-synthesis, in which findings are integrated across studies to offer novel interpretations of the evidence (Walsh & Downe, 2005). We compiled and organized findings within the domains of interest that structured the data extraction process to create taxonomies of findings to facilitate taxonomic analysis. We developed two initial taxonomies of findings pertaining to (a) psychosocial stressors and (b) adaptive coping strategies, with findings organized separately for PWDs and CGs. Two reviewers (S. Bannon and M. Reichman) iteratively revised the taxonomies to collapse highly similar findings to reduce redundancy and promote concise wording without loss of granularity. As the final stage of our analysis, we examined the taxonomies of findings for PWDs and CGs side-by-side to elucidate the common stressors and coping strategies, and those that are distinct.

Findings

Characteristics of Studies

Figure 1 presents a PRISMA flow chart of the study search and selection process. Our meta-synthesis included 60 articles after the full-text inclusion screen. Supplementary Table 4 displays the participant and study characteristics of all articles included in our review. Included studies were conducted in a number of countries, including the United Kingdom ($N = 17$), Norway ($N = 11$), multiple European countries ($N = 9$), France ($N = 6$), Canada ($N = 6$), Australia ($N = 5$), United States ($N = 3$), South America ($N = 3$), as well as Hong Kong and Israel ($N = 1$ for each). The mean sample size across studies was 25.6 ($SD = 36.0$, range = 1–233). Methods of data collection predominantly

Table 2. CASP Checklist Rating of Included Studies

Criteria	Met criteria (3)	Somewhat met criteria (2)	Did not meet criteria (1)
1. Was there a clear statement of the aims of the research?	48	11	1
2. Is a qualitative methodology appropriate?	60	0	0
3. Was the research design appropriate to address the aims of the research?	41	18	1
4. Was the recruitment strategy appropriate to the aims of the research?	21	26	13
5. Were the data collected in a way that addressed the research issue?	41	18	1
6. Has the relationship between researcher and participants been adequately considered?	7	15	38
7. Have ethical issues been taken into consideration?	44	14	2
8. Was the data analysis sufficiently rigorous?	46	9	5
9. Is there a clear statement of findings?	49	10	1
10. How valuable is the research?	53	4	3

Note: CASP = Critical Appraisal Skills Programme.

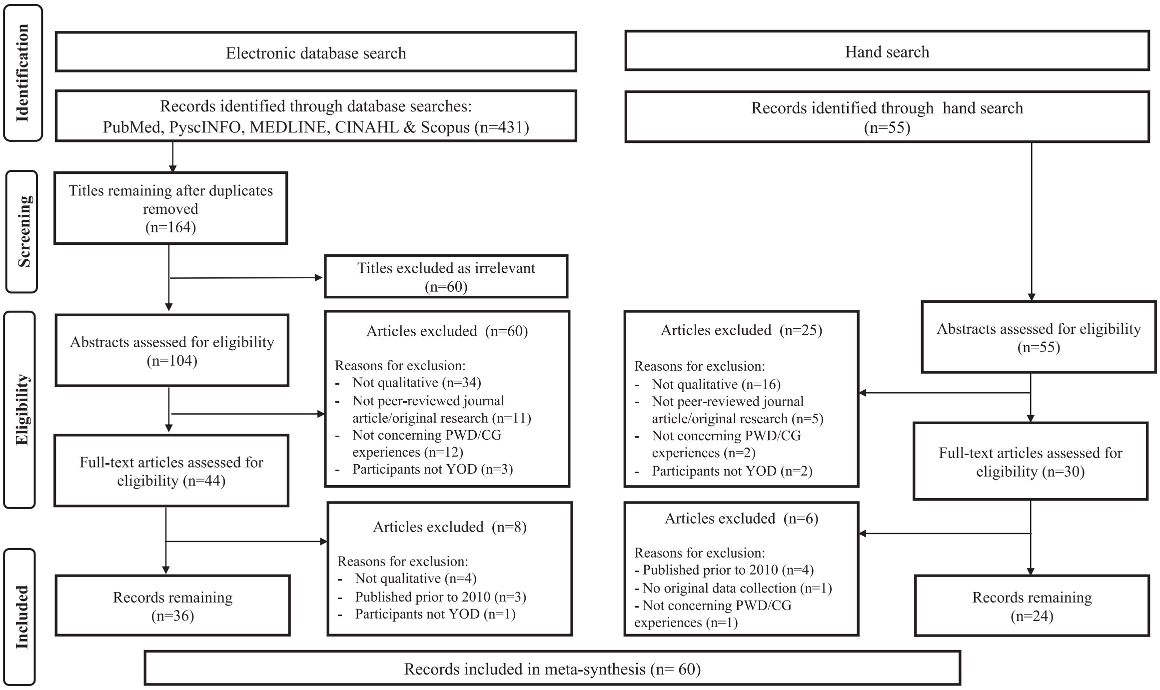

Figure 1. PRISMA flow diagram.

included semistructured interviews of either PWDs (*N* = 26) or CGs (*N* = 29). Few (*N* = 3) studies included dyads of PWD and CGs interviewed together. In addition, some studies included interviews of other individuals (i.e., individual non-CG family members, professional care providers for PWDs) (*N* = 13) or focus groups (*N* = 8) including a combination of PWDs, CGs, other family members, and professional care providers for PWDs.

To analyze qualitative data, studies primarily used thematic analysis (*N* = 24), interpretative phenomenological analysis (*N* = 10), or grounded theory (*N* = 7). Approximately half (48%) of the studies reported on time elapsed since YOD diagnosis for participants. Out of these studies (*N* = 29), 40% reported that individuals were diagnosed on average more than 1 year before study participation. Two studies included both individuals with YOD and later-onset dementia (>65) yet presented findings separately for each group. In addition, some studies focused on specific subtypes of YOD, such as FTD (*N* = 20) and PCA (*N* = 6). CGs included spouses (*N* = 25), children (*N* = 16), and other family members (*N* = 2).

Synthesized Findings

Based on the integration of qualitative findings across the reviewed literature, we identified four meta-synthesis

Table 3. Common Stressors of Persons With YOD and Their Informal Caregivers After Diagnosis

Subtheme	Findings	Supportive literature
Initial impact of the diagnosis	Receiving diagnosis as a shocking, overwhelming event that turns life "upside down"	PWD: Aslett et al. (2019); Dourado et al. (2018); Harding et al. (2018); Hutchinson et al. (2020); Pang and Lee (2019); Roach et al. (2014, 2016); Wawrziczny et al. (2017a, 2017b) CG: Kilty et al. (2019)
	Intense negative emotions and distress (e.g., anxiety, anger, grief, despair, and hopelessness) upon diagnosis	PWD: Carone et al. (2016); Castaño (2020); Johannessen and Möller (2013); Johannessen et al. (2017, 2018, 2019); Pang and Lee (2019); Rostad et al. (2013); Thorsen et al. (2020); van Vliet et al. (2017) CG: Kilty et al. (2019); Roach et al. (2016)
	Difficulty obtaining accurate and helpful information, or feeling overwhelmed with information	CG: Aslett et al. (2019); Carone et al. (2016); Cations et al. (2017); Ducharme et al. (2014); Flynn and Mulcahy (2013); García-Toro et al. (2020); Hoppe (2018); Hutchinson et al. (2016); Jentoft et al. (2014); Johannessen et al. (2016); Lockeridge and Simpson (2013); Millenaar et al. (2018); Oyebode et al. (2013); Stamou et al. (2020); Van Rickstal et al. (2019); Wawrziczny et al. (2017a, 2017b); Werner et al. (2020)
	Difficulty understanding diagnosis and/or disease trajectory	PWD: Harding et al. (2018); Van Rickstal et al. (2019) CG: Ducharme et al. (2013); Flynn and Mulcahy (2013); Hoppe (2018); Millenaar et al. (2014, 2018); Oyebode et al. (2013); Van Rickstal et al. (2019)
	Denial of diagnosis, or difficulty believing and accepting diagnosis and lack of cure	PWD: Carone et al. (2016); Castaño (2020); Clemerson et al. (2014); Flynn and Mulcahy (2013); Johannessen et al. (2017); Lockeridge and Simpson (2013); Millenaar et al. (2018); Rostad et al. (2013) CG: García-Toro et al. (2020); Hutchinson et al. (2016); Lockeridge and Simpson (2013); Millenaar et al. (2018); Pang and Lee (2019)
	Sense of loss of anticipated future and "golden years"	PWD: Busted et al. (2020); Harding et al. (2018) CG: Cations et al. (2017); Ducharme et al. (2013); Harding et al. (2018); Kilty et al. (2019); Pang and Lee (2019); Wawrziczny et al. (2017a, 2017b)
	Lack of acceptance or denial of one partner interfering in couple's ability to adjust together[a]	Lockeridge and Simpson (2013); Millenaar et al. (2018); Van Rickstal et al. (2019); Wawrziczny, Antoine et al. (2016)
YOD symptoms and illness progression	Deterioration in cognitive and behavioral abilities in person with YOD (e.g., challenges with memory, concentration, communication, and regulation of emotions) and personality changes (e.g., disinhibition, apathy, and aggression)	PWD: Arntzen et al. (2016); Busted et al. (2020); Castaño (2020); Flensner and Rudolfsson (2018); Johannessen and Möller (2013); Johannessen et al. (2018); Lockeridge and Simpson (2013); Nichols et al. (2013); Rabanal et al. (2018); Roach and Drummond (2014); Thorsen et al. (2020) CG: Ducharme et al. (2013); Johannessen et al. (2017); Lockeridge and Simpson (2013); Nichols et al. (2013); Oyebode et al. (2013); Svanberg et al. 2010); van Vliet et al. (2017)
	Unpredictability of symptom presentation and severity on day-to-day basis, leading to fluctuating "good" and "bad" days and uncertainty in effectiveness of compensatory strategies	PWD: Busted et al. (2020); Harding et al. (2018); Holthe et al. (2018) CG: Aslett et al. (2019); García-Toro et al. (2020); Hutchinson et al. (2016); Svanberg et al. (2010); Wawrziczny, Antoine et al. (2016)
	Embarrassment, insecurity, guilt, and shame related to cognitive and behavioral symptoms of person with YOD	PWD: Busted et al. (2020); Clemerson et al. (2014); Hewitt et al. (2013); Johannessen and Möller (2013); Johannessen et al. (2018, 2019); Thorsen et al. (2020); Wawrziczny, Pasquier et al. (2016); Werner et al. (2020) CG: Ducharme et al. (2013); Nichols et al. (2013); Oyebode et al. (2013); Werner et al. (2020)

Table 3. Continued

Subtheme	Findings	Supportive literature
	Disappointment, anxiety, and distress over perceptible nature of symptom progression and deterioration of person with YOD	PWD: Castaño (2020); Pipon-Young et al. (2012); Thorsen et al. (2020) CG: Hutchinson et al. (2016); Lockeridge and Simpson (2013)
	Uncertainty regarding the future and the illness progression	PWD: Harding et al. (2018); Holthe et al. (2018) CG: Millenaar et al. (2014); Pang and Lee (2019); Van Rickstal et al. (2019)
	Feeling emotionally overwhelmed (e.g., sadness, anxiety, and fear) by the future knowing the progressive nature of the illness	PWD: Flynn and Mulcahy (2013); Johannessen et al. (2019); Pipon-Young et al. (2012); Rabanal et al. (2018); Roach and Drummond (2014); Thorsen et al. (2020) CG: Aslett et al. (2019); García-Toro et al. (2020); Johannessen and Möller (2013); Kilty et al. (2019); Larochette et al. (2019); Lockeridge and Simpson (2013); Metcalfe et al. (2019); Millenaar et al. (2018); Oyebode et al. (2013); Pang and Lee (2019)
Disruptions in family or social relationships	Experiences of stigma or judgment from others, and accompanying difficulty disclosing diagnosis for fear of negative reactions	PWD: Carone et al. (2016); Castaño (2020); Clemerson et al. (2014); Johannessen and Möller (2013); Johannessen et al. (2017, 2018); Lockeridge and Simpson (2013); Pipon-Young et al. (2012); Sakamoto et al. (2017); Thorsen et al. (2020); van Vliet et al. (2017); Werner et al. (2020) CG: Ducharme et al. (2013); Hoppe (2018); Hutchinson et al. (2016); Nichols et al. (2013); Wawrziczny, Antoine et al. (2016); Werner et al. (2020)
	Social isolation caused by others distancing themselves and loss of friends	PWD: Busted et al. (2020); Carone et al. (2016); Cations et al. (2017); Clemerson et al. (2014); Hewitt et al. (2013); Hutchinson et al. (2020); Johannessen et al. (2018); Kinney et al. (2011); Lockeridge and Simpson (2013); Pipon-Young et al. (2012); Roach and Drummond (2014); Robertson and Evans (2015); Rostad et al. (2013); Sakamoto et al. (2017); van Vliet et al. (2017); Werner et al. (2020) CG: Evans (2019); Hutchinson et al. (2016); Oyebode et al. (2013); Pang and Lee (2019); Svanberg et al. (2010); Wawrziczny et al. (2017a (2017b)
	Feelings of loneliness and lack of social support	PWD: Clemerson et al. (2014); Ducharme et al. (2014); Giebel et al. (2020); Johannessen and Möller (2013); Pipon-Young et al. (2012); Thorsen et al. (2020); Wawrziczny et al. (2016) CG: Aslett et al. (2019); Carone et al. (2016); Cations et al. (2017); Dourado et al. (2018); Flynn and Mulcahy (2013); García-Toro et al. (2020); Hutchinson et al. (2016, 2020); Johannessen et al. (2017); Kilty et al. (2019); Kimura et al. (2015); Kinney et al. (2011); Lockeridge and Simpson (2013); Millenaar et al. (2018); Pang and Lee (2019); Roach et al. (2014); Wawrziczny, Antoine, et al. (2016, 2017a, 2017b); Werner et al. (2020)
	Difficulty explaining diagnosis to children and managing their emotions and reactions	PWD: Busted et al. (2020) CG: Aslett et al. (2019); Flensner and Rudolfsson (2018); Flynn and Mulcahy (2013); Gelman and Rhames (2020); Kilty et al. (2019); Millenaar et al. (2014); Oyebode et al. (2013)
	Family conflict, tension, and disconnection	PWD: Hutchinson et al. (2020); Thorsen et al. (2020) CG: García-Toro et al. (2020); Gelman and Rhames (2020); Millenaar et al. (2014); Oyebode et al. (2013); Svanberg et al. (2010)
	Concern for children regarding genetic nature of disease	CG: Aslett et al. (2019); García-Toro et al. (2020); Hutchinson et al. (2016)

Table 3. Continued

Subtheme	Findings	Supportive literature
Changes and strain in couples' relationship[a]	Changing roles and responsibilities within family	Aslett et al. (2019); Gelman and Rhames (2020); Harding et al. (2018); Hutchinson et al. (2020); Kimura et al. (2015); Kinney et al. (2011); Millenaar et al. (2014, 2018); Nichols et al. (2013); Oyebode et al. (2013); Roach et al. (2016); Wawrziczny, Antoine, et al. (2016); Wawrziczny, Pasquier, et al. (2016)
	Perceived change in feeling like a "couple," and loss of relationship reciprocity	Bakker et al. (2010); Flynn and Mulcahy (2013); Johannessen et al. (2017); Millenaar et al. (2018); Kilty et al. (2019); Kimura et al. (2015); Pang and Lee (2019); Wawrziczny, Antoine, et al. (2016)
	Changes in intimacy and sexual relationship in couple	Carone et al. (2016); Kimura et al. (2015); Lockeridge and Simpson (2013); Millenaar et al. (2018)
	Feeling disconnected and distanced from each other	Oyebode et al. (2013); Wawrziczny, Pasquier, et al. (2016)
	Discrepancies in recollection of experiences	Harding et al. (2018)
	Navigating increasing dependence, including managing disagreements over person with YOD's abilities and treatment needs	Aslett et al. (2019); Harding et al. (2018); Johannessen et al. (2017); Roach et al. (2014); Wawrziczny, Antoine et al. (2016); Wawrziczny, Pasquier et al. (2016)
	Lack of trust and strain on relationship	Hutchinson et al. (2020); Pipon-Young et al. (2012)
	Increased conflict between partners	Flynn and Mulcahy (2013); Lockeridge and Simpson (2013)
Barriers to coping together as a couple[a]	Poor previous relationship functioning serving as barrier to managing new difficulties as a team	Aslett et al. (2019); Harding et al. (2018)
	Challenges navigating both partners' need for independence amid increasing reliance (e.g., caregiver serving in overprotective role and leading person with YOD to feel disempowered)	Castaño (2020); Clemerson et al. (2014); Johannessen et al. (2017); Wawrziczny, Pasquier, et al. (2016)
	Challenges with open communication and deterioration in communication	Aslett et al. (2019); Larochette et al. (2019); Nichols et al. (2013); Oyebode et al. (2013); Pang and Lee (2019); Roach et al. (2014); Stamou et al. (2020); Wawrziczny, Antoine, et al. (2016)
	Fear of burdening each other	Svanberg et al. (2010)
	Avoidance of discussing plans for the future, especially future living situations and end-of-life care preferences	Roach et al. (2016); Van Rickstal et al. (2019); Wawrziczny, Antoine, et al. (2016); Wawrziczny, Pasquier, et al. (2016)
	Total loss of verbal communication, because of language impairment or withdrawal	Larochette et al. (2019)

Notes: CG = caregiver; PWD = person with dementia; YOD = young-onset dementia.

[a]Findings that are dyadic in nature, or related to the relationship between PWD and CG.

themes: (a) *common* psychosocial stressors experienced by both PWDs and CGs, (b) *unique* psychosocial stressors experienced by either PWDs or CGs, (c) *common* adaptive coping strategies of PWDs and CGs, and (d) *unique* adaptive coping strategies of PWDs or CGs. Tables 3 and 4 and Supplementary Tables 2 and 3 present the subthemes and specific findings associated with each theme along with the literature supporting each finding. Stressors and adaptive coping strategies that pertain to PWDs and CGs as a unit or to the PWD–CG relationship (i.e., dyadic) are denoted in the tables with an asterisk.

Theme 1: Common Stressors of Persons With YOD and Informal CGs

Our review elucidated the various forms of psychosocial stressors that are *common* among PWDs and CGs (Table 3). We organized common stressors into the following subthemes: (a) initial impact of the diagnosis, (b)

Table 4. Common Adaptive Coping Strategies of Persons With YOD and Their Informal Caregivers After Diagnosis

Subtheme	Findings	Supportive literature
Avoidance and denial	Minimizing the diagnosis (e.g., saying "memory problems") or concealing the diagnosis, pain, or needs from others	PWD: Castaño (2020); Hoppe (2018); Hutchinson et al. (2016, 2020); Johannessen et al. (2018, 2019); Pipon-Young et al. (2012); Rabanal et al. (2018); Thorsen et al. (2020); van Vliet et al. (2017) CG: Lockeridge and Simpson (2013); Nichols et al. (2013); Pang and Lee (2019); Svanberg et al. (2010); Wawrziczny, Antoine, et al. (2016); Werner et al. (2020)
	Detaching emotionally, cognitive avoidance, and denial	PWD: Lockeridge and Simpson (2013) CG: García-Toro et al. (2020); Hutchinson et al. (2016); Larochette et al. (2019); Lockeridge and Simpson (2013); Svanberg et al. (2010)
	Adopting avoidance together as a couple[a]	Wawrziczny, Antoine, et al. (2016); Wawrziczny, Pasquier, et al. (2016)
Acceptance	Seeking more information and education about disease and progression to develop realistic understanding	PWD: Clemerson et al. (2014); Johannessen and Möller (2013); Stamou et al. (2020) CG: Bakker et al. (2010); Ducharme et al. (2013); García-Toro et al. (2020); Johannessen and Möller (2013); Nichols et al. (2013); Oyebode et al. (2013); Svanberg et al. (2010); Wawrziczny et al. (2017a, 2017b); Werner et al. (2020);
	Taking time to process diagnosis, negative feelings, and grief	PWD: Johannessen and Möller (2013); Johannessen et al. (2018); Van Rickstal et al. (2019 CG: Bakker et al. (2010); Ducharme et al. (2013); Flensner and Rudolfsson (2018); Svanberg et al. (2010)
	Cultivating acceptance of the diagnosis, changes, losses, and future progression as something entirely outside of one's control	PWD: Castaño (2020); Johannessen and Möller (2013); Johannessen et al. (2019); Rostad et al. (2013); van Vliet et al. (2017); Wawrziczny, Antoine, et al. (2016) CG: Dourado et al. (2018); Flensner and Rudolfsson (2018); García-Toro et al. (2020); Larochette et al. (2019); Millenaar et al. (2018); Oyebode et al. (2013); Pang and Lee (2019); Roach and Drummond (2014); Svanberg et al. (2010); Wawrziczny et al. (2016, 2017a, 2017b)
	Acknowledging impending decline together as a couple to cultivate acceptance together[a]	Harding et al. (2018); Nichols et al. (2013)
	Normalizing symptom-specific dependencies as a way the couple works together to manage life's challenges[a]	Harding et al. (2018); Warrziczny, Antoine, et al. (2016); Wawrziczny, Pasquier, et al. (2016)
Present focus	Staying present in the current moment and focused on one day at a time to manage uncertainty	PWD: Busted et al. (2020); Castaño (2020); Clemerson et al. (2014); Harding et al. (2018); Johannessen et al. (2018, 2019); Rabanal et al. (2018); Roach et al. (2014); Wawrziczny, Antoine, et al. (2016) CG: Roach and Drummond (2014); Van Rickstal et al. (2019)
	Taking a day-by-day approach together as a couple[a]	Harding et al. (2018); Roach et al. (2014); Wawrziczny, Antoine, et al. (2016); Wawrziczny, Pasquier, et al. (2016)
Individual and collaborative problem-solving	Using routines and schedules to maintain controlled environment for person with YOD and to maintain a sense of normality	PWD: Arntzen et al. (2016); Busted et al. (2020); Carone et al. (2016); Evans (2019); Harding et al. (2018); Hewitt et al. (2013); Jentoft et al. (2014); Kinney et al. (2011); Pipon-Young et al. (2012); Rabanal et al. (2018); Ritchie et al. (2018); Rostad et al. (2013) CG: Carone et al. (2016); Flensner and Rudolfsson (2018); Jentoft et al. (2014); Lockeridge and Simpson (2013); Nichols et al. (2013); Svanberg et al. (2010)
	Problem-solving specific symptoms and behaviors to develop compensatory strategies and adaptations to assist with person with YOD's activities of daily living	PWD: Arntzen et al. (2016); Busted et al. (2020); Castaño (2020); Harding et al. (2018); Hewitt et al. (2013); Holthe et al. (2018); Jentoft et al. (2014); Johannessen and Möller (2013); Johannessen et al. (2018, 2019); Oyebode et al. (2013); Rabanal et al. (2018); Ritchie et al. (2018); Rostad et al. (2013); Stamou et al. (2020); Thorsen et al. (2020); van Vliet et al. (2017) CG: Arntzen et al. (2016); García-Toro et al. (2020); Harding et al. (2018); Hoppe (2018); Jentoft et al. (2014); Millenaar et al. (2014); Oyebode et al. (2013); Pipon-Young et al. (2012); Svanberg et al. (2010); van Vliet et al. (2017); Wawrziczny (Antoine et al. (2016); Wawrziczny, Pasquier, et al. (2016); Wawrziczny et al. (2017a, 2017b)

Table 4. Continued

Subtheme	Findings	Supportive literature
	Adopting a "teamwork" approach to managing difficulties and engaging in joint problem-solving in service of the shared project of preserving normal everyday life[a]	Harding et al. (2018); Holthe et al. (2018); Roach et al. (2014); Svanberg et al. (2010); Wawrziczny, Antoine et al. (2016); Wawrziczny, Pasquier, et al. (2016); Wawrziczny et al. (2017a, 2017b)
	Reallocation of responsibilities within the couple or family[a]	Harding et al. (2018); Stamou et al. (2020)
	Collaborative efforts to maintain person with YOD's independence and ability to stay engaged in everyday life and contribute to family life[a]	Ducharme et al. (2014); Jentoft et al. (2014); Millenaar et al. (2014); van Vliet et al. (2017); Wawrziczny, Antoine et al. (2016); Wawrziczny, Pasquier, et al. (2016); Wawrziczny et al. (2017a, 2017b)
	Flexibility in problem-solving and support provision[a]	Metcalfe et al. (2019); Wawrziczny, Antoine et al. (2016); Wawrziczny, Pasquier, et al. (2016)
Social support	Openness about diagnosis with friends and family members, and willingness to engage in dialogue with others about diagnosis and experience	PWD: Busted et al. (2020); Clemerson et al. (2014); Johannessen and Möller (2013); Pipon-Young et al. (2012); Robertson and Evans (2015); Sakamoto et al. (2017); Thorsen et al. (2020); van Vliet et al. (2017) CG: Ducharme et al. (2013); Flensner and Rudolfsson (2018); García-Toro et al. (2020); Metcalfe et al. (2019); Millenaar et al. (2018); Nichols et al. (2013); Svanberg et al. (2010); van Vliet et al. (2017); Werner et al. (2020)
	Staying connected to others and maintaining close relationships to fight social isolation and for acceptance and support	PWD: Busted et al. (2020); Carone et al. (2016); Clemerson et al. (2014); Hewitt et al. (2013); Hoppe (2018); Johannessen and Möller (2013); Johannessen et al. (2016, 2018, 2019); Kinney et al. (2011); Oyebode et al. (2013); Pipon-Young et al. (2012); Rabanal et al. (2018); Ritchie et al. (2018); Sakamoto et al. (2017); Stamou et al. (2020); Thorsen et al. (2020); van Vliet et al. (2017); Wawrziczny (Antoine et al. (2016); Wawrziczny, Pasquier, et al. (2016) CG: Carone et al. (2016); Flynn and Mulcahy (2013); García-Toro et al. (2020); Hoppe (2018); Kinney et al. (2011); Lockeridge and Simpson (2013); Svanberg et al. (2010); Wawrziczny et al. (2017a, 2017b)
	Connecting with others with YOD or similar experiences to find peer understanding and support	PWD: Carone et al. (2016); Castaño (2020); Johannessen et al. (2017); Mayrhofer, Mathie, et al. (2020); Pipon-Young et al. (2012); Rabanal et al. (2018); Stamou et al. (2020) CG: Roach and Drummond (2014); Carone et al. (2016); Cations et al. (2017); Dourado et al. (2018); García-Toro et al. (2020); Hutchinson et al. (2020); Lockeridge and Simpson (2013); Mayrhofer, Mathie, et al. (2020); Millenaar et al. (2014); Svanberg et al. (2010); Wawrziczny et al. (2017a, 2017b)
	Making connections to the outside world as a couple, socializing as a couple, and attending meetings for support as a couple[a]	Ducharme et al. (2014); Johannessen et al. (2017); Wawrziczny (Antoine et al. (2016); Wawrziczny, Pasquier, et al. (2016)
Cultivating positive emotions	Gratitude—recognizing how situation could be worse and appreciating one's life and abilities	PWD: Clemerson et al. (2014); Johannessen et al. (2019); Pipon-Young et al. (2012); Roach and Drummond (2014); Thorsen et al. (2020); van Vliet et al. (2017) CG: Oyebode et al. (2013); Roach and Drummond (2014)
	Positivity, staying in good spirits, and recognizing positive attributes of person with YOD	PWD: Clemerson et al. (2014); Johannessen et al. (2018); Rabanal et al. (2018); Rostad et al. (2013) CG: García-Toro et al. (2020); Hutchinson et al. (2016); Larochette et al. (2019); Nichols et al. (2013); Pang and Lee (2019); Robertson and Evans (2015); Svanberg et al. (2010); Van Rickstal et al. (2019); Wawrziczny et al. (2017a, 2017b)
	Laughing and using humor in the context of YOD and symptoms	PWD: Thorsen et al. (2020) CG: Oyebode et al. (2013); Roach and Drummond (2014); Svanberg et al. (2010)

Table 4. Continued

Subtheme	Findings	Supportive literature
	Finding comfort through faith and spirituality	PWD: Pipon-Young et al. (2012) CG: García-Toro et al. (2020); Pang and Lee (2019)
	Engaging in pleasurable, fun, and leisure activities that boost one's mood, especially with family members, and using adaptations as needed	PWD: Busted et al. (2020); Carone et al. (2016); Ducharme et al. (2014); Flesner and Rudolfsson (2018); Hewitt et al. (2013); Jenoft et al. (2014); Johannessen and Möller (2013); Johannessen et al. (2016, 2018, 2019); Kinney et al. (2011);Pipon-Young et al. (2012); Rabanal et al. (2018); Rostad et al. (2013); Stamou et al. (2020); Thorsen et al. (2020); van Vliet et al. (2017) CG: Bakker et al. (2010); Ducharme et al. (2014); Flensner and Rudolfsson (2018); García-Toro et al. (2020); Hewitt et al. (2013); Hutchinson et al. (2016); Jentoft et al. (2014); Johannessen et al. (2017); Kinney et al. (2011); Larochette et al. (2019); Lockeridge and Simpson (2013); Millenaar et al. (2014, 2018); Nichols et al. (2013); Oyebode et al. (2013); Roach et al. (2016); Wawrziczny et al. (2017a, 2017b)
	Engaging in pleasurable activities together as a couple[a]	Holthe et al. (2018); Jentoft et al. (2014); Johannessen et al. (2016); Oyebode et al. (2013); Pang and Lee (2019); Roach et al. (2014, 2016)
Meaning making	Sharing one's story and participating in advocacy	PWD: Castaño (2020); Pipon-Young et al. (2012); Sakamoto et al. (2017); Stamou et al. (2020) CG: Kinney et al. (2011); Lockeridge and Simpson (2013); Nichols et al. (2013)
	Continuing work as long as possible and preserving engagement in activities that generate a sense of meaning and purpose	PWD: Evans (2019); Hewitt et al. (2013); Holthe et al. (2018); Kinney et al. (2011); Oyebode et al. (2013); Pipon-Young et al. (2012); Rabanal et al. (2018); Roach et al. (2016); Robertson and Evans (2015); Sakamoto et al. (2017); Thorsen et al. (2020) CG: Dourado et al. (2018); Johannessen et al. (2017); Roach et al. (2016); Stamou et al. (2020)
Adaptive communication[a]	Keeping things from each other that would be damaging	Lockeridge and Simpson (2013); Svanberg et al. (2010)
	Open communication with each other, including about limitations of abilities and caregiver's care and preferences for future care and end-of-life care	Millenaar et al. (2018); Stamou et al. (2020); Van Rickstal et al. (2019); Wawrziczny (Antoine et al. (2016); Wawrziczny, Pasquier, et al. (2016)
	Developing a new language to communicate with one another to understand needs, and accepting lack of verbal communication when necessary	García-Toro et al. (2020); Kinney et al. (2011); Larochette et al. (2019); Stamou et al. (2020)
Interpersonal connection[a]	Expressing gratitude for support	Harding et al. (2018); Kilty et al. (2019)
	Expressing patience with each other and not showing frustration	Pang and Lee (2019)
	Cultivating a strong sense of togetherness by having special moments between partners where "reconciliation" can be felt, and finding new way to be close	Flensner and Rudolfsson (2018); Holthe et al. (2018); Jentoft et al. (2014); Johannessen et al. (2016); Oyebode et al. (2013); Pang and Lee (2019); Roach et al. (2014, 2016); Wawrziczny, Antoine et al. (2016); Wawrziczny, Pasquier, et al. (2016)
	Well-being of one partner strengthens well-being of other	Wawrziczny, Antoine et al. (2016); Wawrziczny, Pasquier, et al. (2016)

Notes: CG = caregiver; PWD = person with dementia; YOD = young-onset dementia.

[a] Findings that are dyadic in nature, or related to the relationship between PWD and CG.

YOD symptoms and illness progression, (c) disruptions in family or social relationships, (d) changes and strain in couples' relationship, and (e) barriers to coping together as a couple. PWDs and CGs both experienced intense negative emotions of anger, grief, despair, and hopelessness (Castaño, 2020; Johannessen et al., 2018, 2019; Thorsen et al., 2020) related to the diagnosis and experienced the diagnosis as turning life "upside down" (Aslett et al., 2019; Hutchinson et al., 2020; Kilty et al., 2019; Pang & Lee, 2019). Both PWDs and CGs faced considerable difficulty accepting the progressive and ultimately terminal nature of the illness being diagnosed (Castaño, 2020; García-Toro et al., 2020; Johannessen et al., 2017; Pang & Lee, 2019), and endorsed challenges associated with obtaining information and understanding the expected disease trajectory (Aslett et al., 2019; García-Toro et al., 2020; Stamou et al., 2020; Werner et al., 2020). When considering the age of onset of symptoms and gravity of the diagnosis, many PWDs and CGs felt they "had a lot of future plans that [they] had to let go" (Millenaar et al., 2018), sometimes exacerbated by the feeling they were only just entering their "golden years" (Harding et al., 2018).

In terms of the symptom progression, both PWDs and CGs experienced the deterioration in the cognitive and behavioral abilities of the PWD as a stressor (Busted et al., 2020; Castaño, 2020; Johannessen et al., 2018; Thorsen et al., 2020). Both PWDs and CGs described the experience of observing potential signs of deterioration as stressful both due to the uncertainty of the future illness progression (Busted et al., 2020; Carone et al., 2016; Holthe et al., 2018; Pang & Lee, 2019) and the unpredictability of the day-to-day symptom presentation (Aslett et al., 2019; Busted et al., 2020; Castaño, 2020; García-Toro et al., 2020), as "difficulties were not reliably ever-present" (Harding et al., 2018) and the "fluctuation in good and bad days" was experienced as a "roller coaster" (Castaño, 2020). PWDs and CGs also both experienced stressors related to social relationships and support, including feelings of loneliness (García-Toro et al., 2020; Hutchinson et al., 2020; Thorsen et al., 2020; Werner et al., 2020) and social isolation (Busted et al., 2020; Evans, 2019; Hutchinson et al. 2020; Werner et al., 2020). For both members of the couple, "the social circle [was] kept at a distance" (Wawrziczny, Antoine, et al., 2016). Within dyads, PWDs and CGs faced changing roles and responsibilities, increasing relationship strain (Hutchinson et al., 2020; Pipon-Young et al., 2012) and a sense of disconnection (Oyebode et al., 2013; Wawrziczny, Antoine, et al., 2016). Relationship strain and disconnection were exacerbated by difficulties with communication (Aslett et al., 2019; Larochette et al., 2019; Pang & Lee, 2019; Stamou et al., 2020), discrepancies in recollections of experiences (Harding et al., 2018), disagreements over abilities and treatment needs of the PWD (Aslett et al., 2019; Harding et al., 2018; Johannessen et al., 2017; Wawrziczny, Pasquier, et al., 2016), and difficulty navigating both persons' needs for independence (Aslett et al., 2019; Harding et al., 2018; Johannessen et al., 2017; Wawrziczny, Antoine, et al., 2016).

Theme 2: Unique Stressors of Persons With YOD and Informal CGs

We also identified a number of *unique* psychosocial stressors that are organized into the following subthemes: (a) initial impact of the diagnosis, (b) YOD symptoms and illness progression, (c) disruptions in family or social relationships, (d) loss, (e) increasing dependence and caregiving burden, and (f) navigating an uncertain future (Supplementary Table 2). For PWDs, many unique psychosocial stressors pertained to their firsthand experience of YOD, including confrontation with their mortality after receiving a diagnosis (Castaño, 2020; Clemerson et al., 2014; Johannessen & Möller, 2013), the devastation of losing the ability to communicate (Busted et al., 2020; Nichols et al., 2013), and feelings of uselessness and lack of purpose (Evans, 2019; Hutchinson et al., 2020; Johannessen et al., 2018, 2019). Feelings of uselessness and the "expanding experience of losing control" were reported as often provoking a sense of "existential anxiety" (Johannessen et al., 2018) for PWDs. For CGs, unique psychosocial stressors largely pertained to their experience of caregiving, including burden related to feeling constant worry for the PWD's well-being (Arntzen et al., 2016; Cations et al., 2017; Flensner & Rudolfsson, 2018; Wawrziczny et al., 2017b) and the need to assume the full head of household responsibilities (Bakker et al., 2010; Gelman & Rhames, 2020; Oyebode et al., 2013). These increasing and shifting responsibilities sometimes led to feelings of "divided loyalties, and guilt" (Kilty et al., 2019), and gave rise to additional challenges finding personal time and engaging in self-care (Aslett et al., 2019; García-Toro et al., 2020; Hutchinson et al., 2020; Larochette et al., 2019).

For some subthemes, similar psychosocial stressors were experienced by PWDs and CGs, though for different reasons. For example, both PWDs and CGs experienced tremendous loss as a result of YOD. PWDs' description of the experience of loss largely surrounded the loss of their identity (Busted et al., 2020; Castaño, 2020; Rabanal et al., 2018; Thorsen et al., 2020), work (Evans, 2019; Hutchinson et al., 2020; Johannessen et al., 2019; Mayrhofer, Mathie, et al., 2020), energy (Johannessen et al., 2018, 2019; Oyebode et al., 2013), and spirit (Johannessen & Möller, 2013; Pang & Lee, 2019; Thorsen et al., 2020), contributing to a "slow and painful loss of self" (Busted et al., 2020). For CGs, the experience of loss predominantly concerned the loss of a meaningful relationship with the PWD (Aslett et al., 2019; García-Toro et al., 2020; Gelman & Rhames, 2020; Millenaar et al., 2018). CGs described experiencing a number of painful losses in their relationship with the PWD, including loss of intimacy (Hoppe, 2018; Kimura et al., 2015; Oyebode et al., 2013; Roach et al., 2014) and meaningful conversation (Aslett et al., 2019; Nichols et al., 2013; Pang & Lee, 2019), leading CGs to feel that they had completely "lost their [partner] as an intimate person, parent of their children, a friend and partner in work and everyday life" (Wawrzicny et al., 2017b).

Theme 3: Common Adaptive Coping Strategies Used by Persons With YOD and Informal CGs to Manage Psychosocial Stressors

In addition to common psychosocial stressors, we also observed that many adaptive coping strategies were *common* among PWDs and CGs (Table 4). We organized the common coping strategies into the following subthemes: (a) avoidance and denial, (b) acceptance, (c) present focus, (d) individual and collaborative problem-solving, (e) social support, (f) cultivating positive emotions, (g) meaning making, (h) adaptive communication, and (i) interpersonal connection. Though most subthemes related to coping were described as adaptive, both PWDs and CGs described engaging in avoidance and denial as coping strategies, with some helpful and some harmful consequences.

Coping strategies related to avoidance and denial included using euphemisms to downplay the diagnosis (e.g., "memory problems"; Johannessen et al., 2018), concealing the diagnosis from friends and acquaintances (Castaño, 2020; Hutchinson et al., 2020; Johannessen et al., 2019; Werner et al., 2020), not thinking about the diagnosis (García-Toro et al., 2020; Hutchinson et al., 2016; Larochette et al., 2019; Svanberg et al., 2010), and detaching from one's emotions regarding the diagnosis (García-Toro et al., 2020; Larochette et al., 2019; Lockeridge & Simpson, 2013; Svanberg et al., 2010). PWDs and CGs were motivated to adopt avoidant strategies in order to preserve normalcy and protect against stigma, "to be seen as 'normal', to be able to relate to others as usual, and diminish the impact of the disease" (Johannessen et al., 2018). The studies that examined PWDs and CGs together as a dyad also revealed how avoidance and concealment can be adopted by a dyad together, such as through avoiding discussing the diagnosis with each other (Lockeridge & Simpson, 2013; Wawrzicny, Pasquier, et al., 2016), or concealing the reality of YOD symptoms (Wawrzicny, Pasquier, et al., 2016) from each other. While avoidance and denial were cited as helpful in some contexts, many PWDs and CGs realized that these strategies served as barriers to adaptive coping, receipt of services, and planning for the future (Wawrzicny, Pasquier, et al., 2016). For many PWDs and CGs, acceptance and willingness to be open with friends and family were essential to cultivate in order to receive critical social support (Busted et al., 2020; Metcalfe et al., 2019; Thorsen et al., 2020; Werner et al., 2020).

PWDs and CGs described many other overlapping adaptive strategies for coping with the various challenges associated with YOD, including taking time to process one's negative feelings and grief (Ducharme et al., 2013; Flensner & Rudolfsson, 2018; Johannessen & Möller, 2013; Van Rickstal et al., 2019), finding acceptance of the diagnosis (Castaño, 2020; García-Toro et al., 2020; Johannessen et al., 2019; Pang & Lee, 2019), taking a day-by-day approach (Busted et al., 2020; Castaño, 2020; Johannessen et al., 2019; Van Rickstal et al., 2019), and practicing gratitude and positivity (García-Toro et al., 2020; Larochette et al., 2019; Metcalfe et al., 2019; Thorsen et al., 2020). Studies examining PWDs and CGs together also identified dyadic adaptive coping strategies, including adopting a teamwork approach to problem-solving (Harding et al., 2018; Holthe et al., 2018; Wawrzicny et al., 2017b; Wawrzicny, Pasquier, et al., 2016), such as with respect to the "joint project of preserving a normal everyday life" (Holthe et al., 2018). A successful teamwork approach was facilitated by open communication (Stamou et al., 2020; Van Rickstal et al., 2019; Wawrzicny, Antoine, et al., 2016), willingness to adapt communication strategies to the PWD's changing abilities (García-Toro et al., 2020; Kinney et al., 2011; Stamou et al., 2020), and a strong sense of togetherness (Flensner & Rudolfsson, 2018; Johannessen et al., 2016; Pang & Lee, 2019; Roach et al., 2016).

Theme 4: Unique Adaptive Coping Strategies Used by Persons With YOD and Informal CGs to Manage Psychosocial Stressors

We organized *unique* adaptive coping strategies into the following subthemes: (a) acceptance, (b) problem-solving, (c) cultivating positive emotions, (d) meaning making, and (e) social support/communication (Supplementary Table 3). PWDs emphasized the importance of preserving their autonomy (Busted et al., 2020; Clemerson et al., 2014; Evans, 2019; Johannessen et al., 2019) in terms of decision-making and engaging in activities that help them feel a sense of usefulness to others (Castaño, 2020; Sakamoto et al., 2017; Stamou et al., 2020; van Vliet et al., 2017). For example, participating in research studies or advocacy was often reported as a manner for PWDs to voice their story and seek recognition of "their continued presence as fellow human beings in society" (Sakamoto et al., 2017). For CGs, unique coping strategies related to the challenge of navigating the PWD's deterioration, including remembering the illness as the reason for any problematic behaviors (Bakker et al., 2010; Hutchinson et al., 2016; Millenaar et al., 2018; Nichols et al., 2013) and learning how to avoid provoking irritation in the PWD (Harding et al., 2018; Johannessen et al., 2017; Svanberg et al., 2010; Wawrzicny, Pasquier, et al., 2016). CGs reported some strategies for cultivating patience and compassion toward PWDs, including "reminiscing about old memories" and "directing the focus of [interactions] to pleasant topics that lacked conflict" (Nichols et al., 2013). Finally, CGs emphasized the importance of finding breaks from caregiving (Flensner & Rudolfsson, 2018; Johannessen et al., 2017; Larochette et al., 2019; Wawrzicny et al., 2017b), especially in order to solicit social and emotional support.

Discussion

We conducted the first meta-synthesis (60 qualitative studies) to comprehensively characterize *both* common and unique stressors and adaptive coping strategies of PWDs and CGs. Results illustrate the many complex psychosocial stressors experienced by both PWDs and CGs following a YOD diagnosis, and accordingly support the importance of developing psychosocial resources for PWDs and CGs with YOD diagnoses. Our meta-synthesis findings reveal that both PWDs and CGs experience intense negative emotions after diagnosis, challenges navigating the PWD's progressive symptoms, and feelings of loneliness and stigmatization. A large body of quantitative research has demonstrated the negative impacts of these stressors on both PWDs and CGs (Cations et al., 2017; Spreadbury & Kipps, 2019a).

We also found a wealth of data to support the fact that both PWDs and CGs have the ability to engage in adaptive coping strategies to help manage the stressors they experience following YOD diagnosis. This evidence thus supports the feasibility of the development of dyadic interventions to support the PWD and CG as a unit. Our meta-synthesis findings reveal that adaptive coping strategies including finding acceptance, seeking social support, cultivating gratitude and optimism, and problem-solving are helpful for both PWDs and CGs. Our finding that these coping strategies are used by PWDs themselves is particularly important, given that the majority of support resources for YOD are geared toward CGs, with limited psychosocial interventions focusing on the positive adjustment and coping of PWDs. This review's nuanced presentation of the common and unique stressors and coping strategies for PWDs and CGs can directly inform dyadic interventions aimed at teaching skills to decrease emotional distress, improve adjustment to the uncertain symptom trajectory, and optimize quality of life for both PWD and CGs.

Although our review highlights that CGs and PWD can both engage in adaptive coping, the high rates of emotional distress and CG burden observed in this population (Spreadbury & Kipps, 2019a) suggest that the coping strategies adopted by some PWDs and CGs are not sufficiently enabling them to manage the immense psychosocial stressors they face. There are many barriers to adjustment and adaptive coping that must be surmounted, including cognitive and behavioral challenges in PWDs, the ever-changing circumstances resulting from the progressive decline of PWDs, time and resource constraints for CGs, and the overall disruption in family structure and responsibilities that are brought on by YOD diagnoses (Millenaar et al., 2016; Spreadbury & Kipps, 2019b). Psychosocial interventions provided for PWDs and CGs early after diagnosis have the potential to aid PWDs and CGs in overcoming these barriers to develop adaptive coping skills to facilitate adjustment and decrease emotional distress and CG burden throughout the course of the illness progression.

Given that the majority of stressors and coping strategies identified across studies were *common* to both PWDs and CGs, our findings suggest that a dyadic framework may be the best approach to psychosocial interventions in this population. Dyadic interventions where PWDs and CGs participate together allow for adaptive coping skills to be taught to both members of the dyad at the same time, which is efficient and cost-effective. Further, such approaches allow skills related specifically to the relationship (e.g., interpersonal effectiveness, communication skills, and collaborative problem-solving) to be taught to both members of the dyad simultaneously. These skills are necessary for PWDs and CGs to navigate challenging conversations related to care planning and financial and legal decision-making, and to cope with the PWD's progression of symptoms and loss of independent function. Because some stressors are experienced uniquely by PWDs and CGs, a dyadic intervention can also promote understanding and empathy within dyads, to support the maintenance of partnership over the course of the YOD experience. Dyadic interventions delivered early after diagnoses when PWDs still have the ability to meaningfully participate have the potential to dramatically improve quality of life in PWD–CG dyads.

Limitations

Our meta-synthesis was limited by the available qualitative literature, and not all findings may be transferable to the experiences of diverse groups of PWDs and CGs living with YOD. Study samples were predominantly White, and the subthemes identified herein may not fully represent the stressors and coping strategies of more diverse groups of PWDs and CGs. Further, very few ($N = 3$) studies employed a dyadic approach to studying PWD and CG experiences. This implies the need for more studies that focus on dyadic adjustment to YOD.

Implications and Directions for Future Research

The psychosocial stressors and adaptive coping strategies identified in our review can be used to develop psychosocial interventions to support dyads in adjusting to YOD diagnoses and navigating stress and distress in the postdiagnosis period. Stress and coping frameworks have been employed to understand how patients with chronic and life-limiting neurological illnesses (e.g., late-onset dementia, stroke, moderate–severe traumatic brain injury) and their informal CGs cope with persistent challenges. Though such approaches have yet to be used with PWDs and CGs with YOD, they have served as the basis of evidence-based dyadic interventions that prevent emotional distress in both members of dyads (Badr et al., 2019; Bannon et al., 2020; Moon & Adams, 2013; Vranceanu et al., 2020).

In order to support the development of dyadic psychosocial interventions for YOD, additional high-quality qualitative research is needed to better understand: (a) dyadic patterns of stress and coping in the initial postdiagnosis period and adjustment to diagnosis over time, (b) ways in which PWDs and CGs identify and engage in adaptive coping strategies for specific psychosocial stressors, (c) PWD and CG needs and preferences for psychosocial interventions, (d) barriers and facilitators to participation in psychosocial interventions, and (e) individual and dyadic factors that may contribute to the feasibility, acceptability, and utility of psychosocial interventions in YOD. Future studies should also be careful to provide sufficient demographic and descriptive details regarding included participants and to prioritize recruitment and enrollment of individuals from diverse backgrounds.

Conclusion

This meta-synthesis integrated available qualitative evidence on the psychosocial stressors and adaptive coping strategies of PWDs and CGs after a diagnosis of YOD and presented the integrated findings in a novel manner to highlight stressors and coping strategies that are both common and unique among PWDs and CGs. Through our use of the stress and coping framework as well as our dyadic lens, this meta-synthesis generated invaluable data to inform future research and clinical interventions for PWD-CG dyads navigating 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 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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