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Together from the start: A transdiagnostic framework for early dyadic interventions for neurodegenerative diseases

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Abstract

Background: Neurodegenerative diseases (NDDs) are increasingly prevalent and radically alter the lives of individuals and their informal care-partners (together called a dyad). As symptoms progress, dyads are at risk for elevated emotional distress and declines in relationship functioning and quality of life. Psychosocial interventions delivered to dyads early after diagnosis have successfully prevented chronic emotional distress across several chronic illnesses including cancer and acute brain injury. Dyads with NDD could benefit from such interventions, however, they are limited. Because NDDs have symptom profiles that are distinct from other chronic illnesses, they require a unique framework and interventions. Given the limited dyadic interventions and unified symptoms across NDDs, a transdiagnostic framework may help to enhance scalability and efficiency. To address this problem, we developed a transdiagnostic framework that cuts across NDD physical and emotional diagnoses to inform cost-effective and sustainable NDD dyadic interventions.

Methods: To develop this framework, we conducted: (1) a narrative review on dyadic adjustment and existent dyadic interventions for those with NDDs, and (2) integrated findings to develop our NDD transdiagnostic framework for dyadic interventions early after diagnosis.

Results: Findings revealed no existent dyadic interventions for NDDs delivered shortly after diagnosis. Among available interventions, all were delivered later in disease progression, thereby focusing on dyadic challenges at more advanced stages. In addition, although research emphasized the influence of individual, dyadic, and contextual factors on dyads' early adjustment to NDDs, no

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conceptual model has been developed. Informed by theory and current research, we introduce an NDD transdiagnostic framework for couples' early biopsychosocial adjustment. This framework includes NDD specific: contextual factors, illness-related factors, individual and dyadic stressors, adaptive coping strategies, and dyads' resources.

Conclusions: Our NDD transdiagnostic framework can be used to inform early dyadic psychosocial interventions that cut across all NDDs. This approach has important implications for implementation and scalability.

Keywords

dyadic interventions; neurodegenerative disorders; neurological illness; diagnosis

Introduction

Neurodegenerative diseases (NDDs) impact millions and are rapidly increasing with the aging population.[1,2] NDDs encompass conditions unified by the deterioration of neurons that lead to progressive declines in cognitive, emotional, and motor functioning.[1] NDD diagnoses drastically change the lives of both person diagnosed and their informal care-partners (e.g., spouses, children, or other family)—together called a *dyad*.[2] NDDs can substantially disrupt dyads' established roles, identities, relationships, and future plans.[3,4] As a consequence, about 50% of individuals with NDDs and their care-partners experience *early adjustment challenges*, including clinically significant emotional distress (e.g., stress, depression, anxiety) and relationship difficulties (e.g. decreased intimacy, increased conflict).[5–7] Early adjustment challenges are important to address because: (1) stress and coping behaviors are interdependent within dyads, (2) emotional distress and relationship difficulties often become chronic and worsen over time, and (3) early adjustment impacts long-term dyadic illness management and health outcomes.[4,8,9] With advances in NDD diagnostic testing, prevention and early intervention efforts are becoming more possible,[10] and are of critical importance given the increasing rates of NDDs.[1,2]

Distinct from other chronic illnesses, dyads with NDDs cope with a combination of progressive cognitive, behavioral, and/or socio-emotional changes that can impact their identity and relationships.[5,6,11–13] Individuals with NDDs may lack insight into their symptoms, deny the diagnosis, or avoid conversations about the future.[11,12] Care-partners may feel a responsibility to ensure that their partner engages with care, accepts the diagnosis, and plans for the future.[11,12,14] With these conflicting experiences, dyad members are often at odds—disagreeing about symptoms and illness management —which can isolate each partner.[8,12] Individuals with NDDs often fear losing their independence (e.g., working, driving, socializing), identities/roles (e.g., parent, partner), and connection to family and friends.[15] Care-partners experience fear and impending loss of their partner, their relationship, and expected future.[12,16] Though some dyads engage resources, communicate openly, or collaboratively problem-solve,[5,6,8] others turn to less helpful coping strategies, such as avoidance or denial. They then experience a "downward spiral" of early challenges that impact long-term illness management.[8,11] Early support for dyads is critical to: (1) improve dyads' ability to proactively communicate about difficult emotions and topics (e.g., finances, long-term care, the impact of the diagnosis and symptoms), (2) prevent further

distress, relationship strain and conflict, and (3) promote positive adjustment.[12] Early dyadic interventions can provide this support and have the potential mitigate chronic emotional distress, which is treatment resistant and linked to worse health outcomes.[4,9,17,18]

Dyadic adjustment—defined by individual and shared understanding and appraisal of the illness and ways of managing symptoms—can predict each dyad members' health behaviors, self-care, illness management, and engagement in long-term care planning.[4,19] Given the interdependence of dyads' initial adjustment and long-term health, early dyadic interventions are recommended to promote positive biopsychosocial outcomes (e.g., cognitive, physical, and emotional functioning, health care utilization).[4,9,12,20–22] Dyadic psychosocial interventions for other chronic illnesses (e.g., stroke, traumatic brain injury, cancer) delivered shortly after illness onset have helped prevent emotional distress and enhance dyadic adjustment[20,23]—some exhibiting better outcomes than individual therapy.[4,9,20] However, dyadic psychosocial interventions delivered shortly after NDD diagnoses are limited.[12,24]

We propose that an *NDD transdiagnostic framework* capturing dyads' adjustment to a NDD diagnosis is needed to inform innovative and efficient early interventions. By adopting a *transdiagnostic approach* focused on common factors, these frameworks offer several advantages over discrete disease conceptualizations.[25,26] First, they can simplify and optimize patient care by highlighting common factors to address.[25,26] Second, they can be an efficient use of resources compared to condition-specific interventions.[25,26] Third, they allow for flexible tailoring to address individual factors.[26,27] Transdiagnostic interventions have been developed to allow providers to treat heterogeneous dyads within medical settings. An example is a program we developed called Recovering Together aimed at preventing chronic emotional distress in patients with acute neurological illnesses hospitalized in a Neurosciences Intensive Care Unit and their caregivers.[23,25,28]Though no frameworks exist for NDDs early after diagnoses, a recent pilot of emotion-focused couples therapy for dyads with heterogenous NDDs 1-6 years after diagnosis improved relationships and quality of life.[2] Because dyads' early experiences with NDDs are often similar,[15,25,26] a transdiagnostic framework would allow assessing and addressing core dyadic concerns including dyads' early: (1) illness-related changes in functioning, (2) divergent appraisals of NDDs, and (3) emotional and relationship challenges.[5,25,26]

The Current Study

Our study aims are two-fold: (1) conduct a narrative review of literature regarding psychosocial impact of NDDs, existent conceptual models of biopsychosocial adjustment, and available dyadic interventions, and (2) integrate findings to develop an NDD transdiagnostic framework for early dyadic adjustment. This framework may inform treatment targets for dyadic psychosocial interventions that can be tailored for a variety of NDDs and clinical settings.

Methods

We used a narrative review methodology to: (1) provide insight into broad, complex problems, (2) use interpretative synthesizing, creativity, and expert judgment, and (3)

incorporate literature across disciplines.[29] This approach allowed us to creatively synthesize multidisciplinary literature to develop a model that describes dyads' early experiences managing NDD. We included studies written in English and limited our review to adult populations and prevalent NDDs (Alzheimer's disease, Parkinson's disease, multiple sclerosis, Huntington's disease, amyotrophic lateral sclerosis) based on the availability of dyadic research necessary to inform our framework.[30]

We used SANRA guidelines for narrative reviews[31] and a four-step process (identification/collection, article selection, article abstraction, and review/synthesis).[32] We searched four databases (Scopus, APA PsycNet, PubMed/MEDLINE, and Google Scholar) from inception to March 2021. We used the Boolean search modifiers AND, NOT and OR for the following search terms (dyad; dyadic adjustment; psychosocial impact; dyadic intervention) with varying terms for NDD conditions (Alzheimer's disease and other dementias; Parkinson's disease; Huntington's disease; multiple sclerosis; amyotrophic lateral sclerosis). We identified articles that described: (1) the psychosocial impact of NDDs on dyads (e.g., emotional distress, relationship changes), (2) conceptual models of adjustment (e.g., stress and coping, dyadic coping), or (3) dyadic psychosocial interventions for NDDs.[33]

To synthesize findings, we summarized the psychosocial impact, conceptual models, and dyadic interventions for each NDD. We then identified common themes across NDDs to understand dyads' psychosocial adjustment after diagnosis. We integrated these empirical findings with prominent theoretical models (e.g., Dyadic Coping theories) of dyadic adjustment[34,35] to develop our NDD transdiagnostic framework.

Results

Below we present findings from our narrative review of each included condition. Supplemental Table 1 provides a detailed description of the psychosocial impact of each NDD. We included 24 articles on AD, 8 on PD, 11 on MS, 11 on HD, and 7 on ALS in our review that described the psychosocial impact of NDDs, existing conceptual models of adjustment, or available dyadic interventions. Below, we describe existing conceptual models and the available early dyadic interventions for each NDD.

Alzheimer's Disease and Other Dementias

Conceptual Models of Adjustment to AD—Several conceptual models exist for dyadic adjustment to AD.[13] Gallagher-Thompson and colleagues'[36] model highlights intersecting elements of dyadic adjustment across early, middle, and advanced stages of AD. It emphasizes the need for support during *transition points* of noticeable shifts in the dyads' care needs.[36] Additional models highlight the influence of: (1) contextual factors (e.g., demographics, living arrangements, health history), (2) primary stressors (e.g., symptoms, distress), (3) secondary stressors (e.g., dyadic relationship, job strain), (4) coping strategies (e.g., values, resiliency), and (5) external resources (e.g., social support, finances).[37] Prior qualitative and conceptual work emphasizes the importance of understanding the interplay of partners' individual characteristics (e.g., behavioral problems, emotional distress, perceived burden) and dyadic dynamics (e.g., relationship type, communication, closeness) in

connection to long-term dyadic adjustment.[14,16,38] For example, emotional and relationship distress) is higher among dyads' with greater premorbid intimacy and functioning.[4,11,14,38]

Dyadic Interventions for AD—Dyadic interventions for moderate-severe stage AD include both psychoeducation (e.g., common symptoms, illness-management behaviors) and evidence-based coping skills (e.g., mindfulness), and demonstrate consistent positive effects on individual well-being and caregiving outcomes (e.g., burden, wellbeing). [7,39–41] Several skills-based dyadic interventions have shown improvement in dyads' adaptive coping and quality of life[40], patients' cognition (e.g., MMSE scores), sleep (e.g., total sleep time, sleep disruptions), and physical health.[41], and decreased health care utilization and hospitalizations and increased time to admission to higher levels of care.[41]

Recently, dyadic interventions have been developed for *"early stage"* AD (0-2 years post-diagnosis),[42] In a randomized controlled trial, dyads who participated in SHARE, a 6-session intervention designed to help dyads collaboratively plan for the future, reported higher satisfaction, greater reduction in caregiver burden, and more improvements in dyadic communication relative to control.[18] However, no AD dyadic interventions address challenges at the time of diagnosis and very few meaningfully include both dyad members.[39]

Parkinson's Disease

Conceptual Models of Adjustment to PD—To our knowledge, no conceptual models have been developed that describe dyadic adjustment to PD. One model of caregiver stress and appraisal[43,44] includes individual and dyadic factors linked and proposes that caregiver well-being is influenced by: (1) stressors (i.e., physical function, cognitive status, behavior problems), (2) primary appraisal (i.e., hours spent caregiving), (3) mediators (i.e., perceived social support, self-esteem), and (4) secondary appraisal (i.e., perceived level of burden). Researchers tested this model and observed that the quality of dyadic relationship was linked to caregiver burden and quality of life.[43]

Dyadic Interventions for PD—In PD, we identified only one dyadic, nurse delivered intervention for moderate-stage PD.[44] The program delivered skills (problem-solving, communication) to manage daily challenges, promote health behaviors, and engage with resources and positive activities. [44] During exit interviews, participants described the program as useful and acceptable.[44]

Multiple Sclerosis

Conceptual Models of Adjustment to MS—No dyadic conceptual models exist for MS, though there is evidence that the use of dyadic (i.e., shared) coping strategies and framing MS as a "we-illness" is linked to positive emotional adjustment.[45] Qualitative studies of couples facing rapid-progressing MS highlight early challenges, including partners' differing coping styles amidst significant life stressors (e.g., loss of employment, parenting).[6] Couples describe loss of intimacy and relationship conflict in the face of these challenges.[6] Topcu and colleagues[46] conducted a meta-review and proposed a conceptual model of early adjustment among persons with MS,[46] which indicates that: (1) individual

positive coping strategies (e.g., acceptance, problem-solving), (2) individual negative coping strategies (e.g., avoidance, isolation, diagnosis concealment), and (3) external stressors and resources (e.g., support, relationships, diagnostic process) impact early adjustment.

Dyadic Interventions for MS—Though few dyadic interventions exist for MS,[45,47] *Relationship Matters* provides dyads with education on communication, conflict resolution, and relationship maintenance skills.[48] Relative to usual care, dyads in *Relationship Matters* reported better relationship functioning and quality of life at a three-month follow up.[48] Another dyadic resiliency skills intervention was developed using a virtual, 6-session format, with sessions led by an experienced licensed social worker designated as "resiliency coach."[47] The program is geared towards care-partners (2 sessions with persons with MS; 4 sessions for care-partner), with dyadic sessions focused on education, and sessions for care-partners focused on identifying resources and practicing individual coping strategies.[47] Both members reported decreased stress and increased life satisfaction post-intervention and at three-month follow-up.[47] Notably, exit interviews revealed that persons with MS were unhappy with the program given their limited involvement.[47] Dyads expressed preferences for (1) interventions delivered at the time of diagnosis, and (2) skills training for both dyad members simultaneously.[47] For persons with MS, involvement in individual psychosocial interventions led to reductions in emotional distress, improvements in MS symptom management, and several medical outcomes (e.g., new brain lesions, markers of T-cell immune regulation).[49]

Huntington's Disease

Conceptual Models of Adjustment for HD—There are no existing models of dyadic adjustment to HD, and individual models are also limited. However, some describe the impact of predictive testing on emotional adjustment,[50] and highlight the positive influence of modifiable factors, including familial attitudes towards HD, open communication, informed/responsive support networks, and balance of caregiving and individual needs.[50–51]

Dyadic Interventions for HD—Dyadic interventions are particularly important given concerns about passing the HD gene into offspring.[52–53] However, there are no dyadic interventions for HD, and limited individual interventions.[54] One pilot group educational intervention conducted by a nurse and clinical psychologist was associated with improvements in emotional distress and caregiver burden.[55]

Amyotrophic Lateral Sclerosis

Psychosocial Impact and Conceptual Models of Adjustment to ALS—There is only one conceptual model capturing dyadic adjustment to ALS,[56] which highlights the importance of self-efficacy, positive appraisal, and positive coping strategies for managing ALS-related challenges.[56]

Dyadic Interventions for ALS—No dyadic interventions exist for ALS, and individual psychosocial interventions are also limited. Researchers developed a group-based program for individuals with ALS and their care-partners using mindfulness-based stress reduction (MBSR) delivered by two meditation trainers.[57,58] Both dyad members experienced positive

changes in individual coping, well-being, and general resiliency skills based on self-report questionnaires.[57]

Discussion

Dyads experience similar early adjustment challenges (e.g., psychosocial stressors, emotional reactions, and relationship changes) shortly after NDD diagnoses.[3] The physical, cognitive, and socio-emotional changes that accompany NDDs impact dyads' identities, roles, relationships, and future.[2] It is important to intervene on these challenges early because many dyads experience emotional distress after diagnosis that negatively impact communication, care management, health outcomes and health care utilization and cost.[9,12] Early psychosocial interventions can help prevent long-term distress, enhance communication and coping, and meaningful engage both partners (prior to functional decline).[4,59,60] Transdiagnostic conceptualizations of dyads' early adjustment to NDDs are a promising, yet underexplored avenue to inform widely applicable dyadic psychosocial interventions.[25,26] We aimed to develop the first NDD transdiagnostic framework to inform early dyadic interventions.

Summary of Findings across NDDs

NDDs drastically disrupt dyads' lives,[61] and are especially challenging for those with rapid or unremitting disease progression (e.g., primary progressive MS) and high likelihood of heritability (e.g., HD diagnoses).[6,62,63] Dyad members often have complex and differing emotional reactions to diagnoses amid the anticipated losses that accompany NDDs.[11,12,45,46,50,61] Although some adjust well, many have difficulty navigating differing early responses, and cope with denial, limited insight, avoidance, or disagreements.[11,12,45,46,50,61] Without support, approximately 30-50% dyads experience heightened emotional distress that becomes chronic and negatively impacts their relationship and shared illness management.[5,11–14,45,63–65]

Across conceptual models, dyadic biopsychosocial adjustment was influenced by: (1) dyads' demographic background, early adjustment to NDDs, and available support and resources,[18] (2) individual health and dyadic/interpersonal functioning before and after diagnosis,[46,50] (3) individual and dyadic appraisal of stressors,[11,24,43] (4) individual and dyadic coping strategies, and (5) "transition points" marked by declines in functioning.[7,8,46,66] NDD symptoms also contributed to relationship conflict, disagreements about symptom severity, less physical and emotional intimacy, and reactions to role changes, which negatively impacted dyadic adjustment.[6,11,14,16,37,38,45]

Existing dyadic psychosocial interventions for NDDs (AD, MS, and ALS) were well-received and associated with improvements in self-reported psychosocial outcomes (e.g., emotional distress, quality of life, caregiver burden). Most interventions were delivered by clinical psychologists, licensed clinical social workers, and nurses.[41,44,47] Interventionists had clinical expertise with NDDs, and some interventions were co-facilitated (e.g., nurses and clinical psychologists).[44,47] Though very few focused on early disease stages, *SHARE* for AD demonstrated benefits on dyads' communication about care needs, preferences, and proactive care-planning.[18] In addition, *Relationship Matters* for MS improved dyads'

relationships.[48] Several skills-based dyadic interventions for moderate-late AD were associated with patient improvements in cognition, neuropsychiatric symptoms (e.g., agitation, impulsivity), illness management (e.g., immune functioning, aerobic activity, decision making autonomy), care needs (e.g., time to admission to higher levels of care, hospital admissions, care utilization), as well as patient and care-partner general physical health and sleep quality (e.g., total sleep time, number of disruptions).[7,41] However, interventions were limited in that they: (1) rarely provided dyads with *individual* and *dyadic coping* skills, (2) addressed *dyads' changing relationships,* (3) failed to address dyads preferences for post-diagnosis support,[67] and (4) the content almost exclusively focused on the needs of care-partners.[39]

NDD Transdiagnostic Framework for Early Dyadic Interventions

We used our findings and prominent theoretical models of dyadic biopsychosocial adjustment to chronic illness (e.g., Dyadic Coping and Dyadic Illness Adjustment theories),[28,34,35] to develop an NDD transdiagnostic framework to capture early *dyadic biopsychosocial adjustment* (Figure 1). Within our framework, biopsychosocial outcomes can include: (1) physical and health functioning (e.g., functional independence, time to placement in higher levels of care, adherence to medical regimens, healthcare utilization); (2) psychological functioning (e.g., emotional distress, adaptive coping, and resiliency); and (3) social functioning, (e.g., dyadic coping, and relationship functioning).[20,28,34,35] We include bidirectional arrows between individual and dyadic factors to account for the interdependence of perceived stressors, coping strategies, and health outcomes within dyads.[28,34] Table 1 provides definitions and specific examples relevant for dyads navigating NDDs, which we also describe below.

Both *individual* and *dyadic factors* are important for dyadic biopsychosocial adjustment and include *individual* and *dyadic appraisal* of NDDs. Using dyadic adjustment theories,[4,18–19] we define appraisal as how individuals and dyads: (1) understand the NDD, (2) perceive the impact of NDD, and (3) believe symptoms should be managed.[4,21,34] *Individual coping strategies* (e.g., relaxation, mindfulness meditation, self-care) and *dyadic coping strategies* (e.g., open, empathetic communication, collaborative problem solving) help explain dyadic biopsychosocial outcomes—making them key targets of intervention within our framework. Interventions should be adjusted based on *contextual factors* such as the dyad's background, relationship type (e.g., spousal partners, parent-child), and relationship functioning. Interventions should also be tailored to meet the unique needs of dyads based on *illness-related factors* (e.g., early symptoms, distressing symptoms, expected progression). Clinicians should assess dyads' cognitive and emotional functioning, relationship dynamics, unmet needs, and preferences for intervention delivery (e.g., in-person vs. telehealth, audio/visual aids, modality of information delivery).[2,12,68] It is also important to prepare dyads for the emotional and practical challenges that accompany uncertain *symptom progression* and to openly discuss *transition points* that will require changes to their joint management of NDDs. Specifically, clinicians should tailor program content based on available prognostic information and discuss ways of coping with an uncertain illness progression and potentially long periods of caregiving (e.g., relapse-remitting MS). Interventionists should work to

maximize dyads' *external resources* (e.g., financial, health care, and social supports) to promote positive adjustment to NDDs.

Table 2 presents two real-world case examples on how this approach can inform early dyadic interventions. We describe each dyad's presenting concerns (medical and psychosocial) and evidence-based skills that can help improve specific biopsychosocial outcomes. Interventions can be delivered by clinical psychologists, social workers, nurses, or other healthcare providers. Table 3 presents a modular approach based on our prior work iteratively developing evidence-based dyadic interventions for acute neurological illnesses.[23] Interventions should begin with 1-3 general sessions that help dyads' better understand their symptoms and functional impact, cope with difficult emotions and uncertainty, and manage stressors individually and together. [12,23,41] Interventionists can then tailor remaining sessions to dyad's needs (e.g., symptom management, health behaviors, relationship transitions, managing difficult emotions, making meaning from experiences).[12,68] Evidence-based skills from a variety of psychosocial approaches (e.g., mindfulness- and acceptance-based interventions; Cognitive Behavioral Therapy, Dialectical Behavior Therapy, Acceptance and Commitment Therapy; Interpersonal Psychotherapy; Integrative Behavioral Couples Therapy) can be integrated within each session.[20,69] Core skills can be applied across sessions such as: (1) mindfulness (present-moment awareness), (2) dialectics (multiple truths/perspectives co-exist),[69] and (2) communication strategies.[28,34] We encourage interventionists to be flexible regarding delivery modality (e.g., in person, virtual, hybrid) and adaptation of material.[70] Interventions may practice brief mindfulness exercises for those with memory or attention impairments, incorporate tools that support speech or hearing differences, and/or recommend additional services (e.g., support groups) as needed. The goal is to balance fidelity (meet treatment targets) with flexibility (adapt to needs) to promote dyadic adjustment.[20,70]

Implications for Medical Settings

Transdiagnostic dyadic interventions can target the common psychosocial profile of dyads facing NDD diagnoses, including shared early challenges (e.g., NDD symptoms, divergent emotional reactions, changes in roles/ relationships, and loss of expected future).[15,26] These interventions can complement medical care by providing education and skills to enhance coping, health behaviors, and engagement of ongoing support.[4,11,15,41] Ideally, interventions would be integrated within medical care settings (e.g., neurology and geriatric clinics) and delivered by a range of providers (e.g., clinical psychologists, nurses, social workers) with adequate training in non-specific therapeutic skills (e.g., empathic responding, alliance-building), working with NDD patients, and delivering evidence-based skills selected for dyad.[20] Integrating psychosocial care within medical care—as demonstrated in other chronic medical conditions[20,23]—can help engage dyads in care, promote interdisciplinary care, and enhance health outcomes[25,70]

Limitations

There are several key limitations. First, we chose to conduct a narrative review[29] and therefore did not comprehensively review all available literature. Second, we focused on prominent NDDs, and may not fully capture experiences of less prevalent diseases (e.g.,

prion disease). Our review was also limited by the literature on dyadic adjustment to NDDs, which largely focused on self-reported outcomes. More work is needed exploring dyadic adjustment to NDDs from a biopsychosocial lens, and the impact of dyadic interventions on medical outcomes. Finally, although dyadic interventions can be delivered by nurses and social workers,[44,47] none to our knowledge have been integrated into ongoing medical care. Additional research is needed to investigate how dyadic interventions could be integrated into medical settings (e.g., virtual and hybrid approaches, delivery by multidisciplinary teams).

Conclusion

NDDs are a major public health concern that dramatically change the lives of those diagnosed and of their partners. Given the overlapping profiles and psychosocial challenges of NDDs, we developed a novel transdiagnostic framework for dyadic adjustment shortly after diagnosis. Our NDD transdiagnostic framework underscores the importance of addressing specific contextual factors, illness-related factors, individual and dyadic stressors, individual and dyadic adaptive coping strategies, and the dyads' external resources to promote positive dyadic adjustment. This novel framework can help inform treatment targets for dyadic psychosocial interventions. It is a promising approach to ensure fidelity within psychosocial interventions while allowing for the flexible adaptation based on settings, populations, and unique dyadic needs.[70]

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key Points:

- Diagnoses of neurodegenerative diseases are associated with substantial disruptions to daily life linked to heightened emotional distress for both the individual and their informal caregivers (together called dyads)
- NDDs have similar symptom profiles and psychosocial challenges, lending support for a unified (i.e., transdiagnostic) framework for dyadic interventions
- At present no NDD transdiagnostic frameworks exist, and dyads have very few resources available to promote positive biopsychosocial adjustment early after NDD diagnoses
- We conducted a narrative review of dyadic adjustment and interventions for NDDs and used our findings to develop the first NDD transdiagnostic framework for dyadic psychosocial interventions

Why does this matter?

Our novel NDD transdiagnostic framework can be used to inform early dyadic psychosocial interventions that cut across all NDDs and can more easily be scaled up and implemented in multidisciplinary clinical settings.

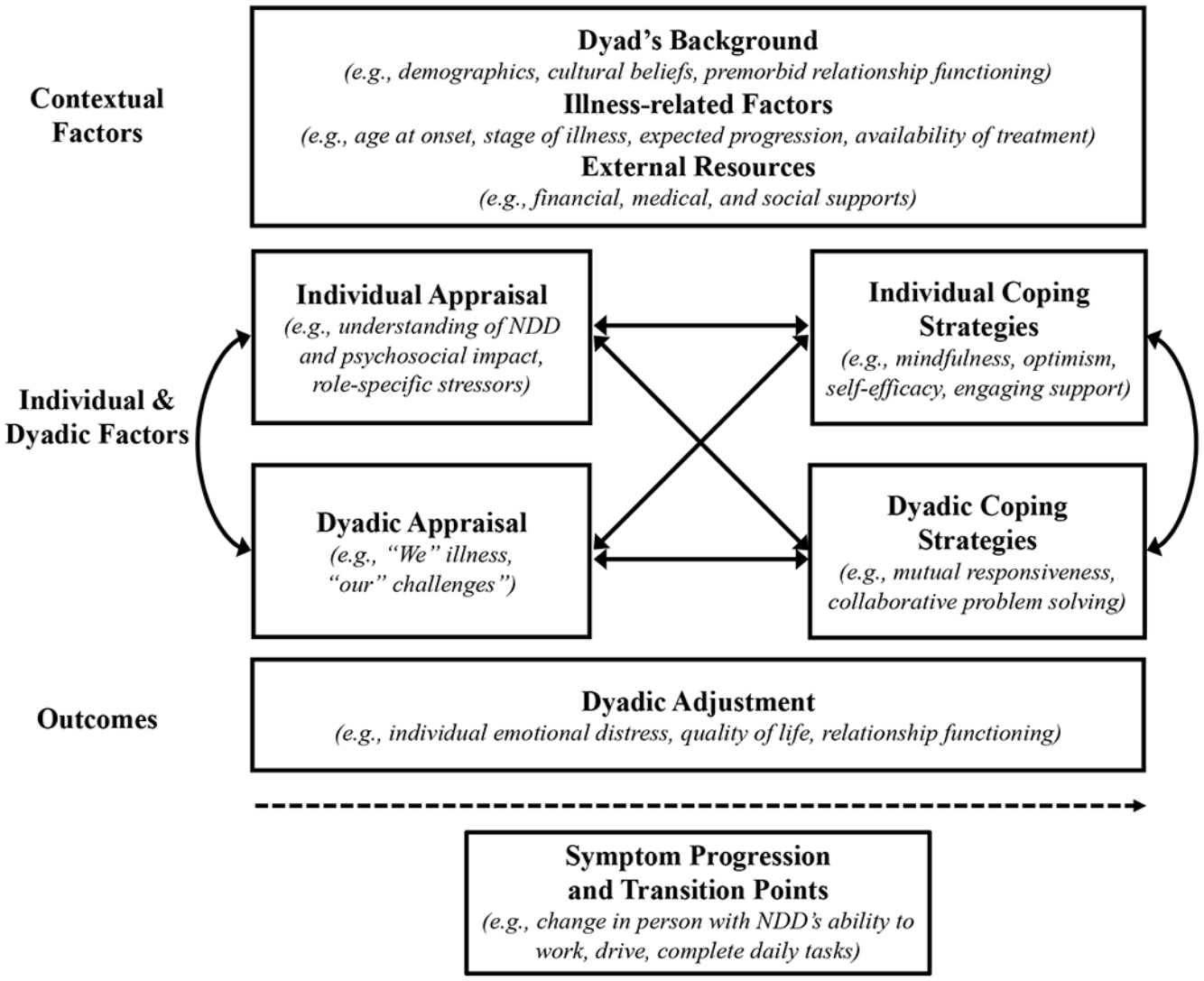

Figure 1.
Transdiagnostic framework to guide early dyadic interventions for NDDs

Table 1.

Components of transdiagnostic framework to guide early dyadic interventions for NDDs

Component	Definition and Examples
Contextual Factors	Definition: Characteristics of individual dyad members and/or the dyadic relationship that may influence the experience of NDDs Examples of Demographic and Contextual factors: • Dyad members' age, gender, and other individual characteristics • Cultural heritage/background and beliefs; comorbid health conditions • Relationship (e.g., spouse, parent-child), roles, & functioning prior to diagnosis
Illness-related factors	Definition: Characteristics of NDDs that contribute to the dyad's adjustment Examples of Illness-related factors: • Timeliness and accuracy of diagnosis; expected progression of illness • Type, number, severity, and specificity of early symptom profile and disruptions on daily living and dyadic relationship • Availability of medical treatments to delay illness progression
External Resources	Definition: Circumstances, assets, and supports available to dyad's that assist in navigating the NDD and related stressors Examples of External Resources: • Presence or absence of financial strain/stability • Financial resources (e.g., socioeconomic status, income, employment stability) • Health care resources (e.g., reliable information on symptoms and expected progression, relationship with providers, connection to psychosocial and practical support for NDD) • Social resources (e.g., availability of caregiving, practical, and emotional support)
Individual Appraisal	Definition: Individual ways of understanding the NDD and its impact Examples of Individual Appraisal: • Understanding of NDD and symptoms (cognitive, physical, behavioral changes), including the attribution of symptoms to NDD, causes, expected progression • Understanding of impact of NDD on daily living and future • NDD care preferences (e.g., ways of managing NDD symptoms, navigating medical visits and decision-making, desired information, and resources for NDD) • Experience of stressors (e.g., emotional reactions to NDD and related stressors) • Illness ownership (e.g., attribution of stressors as individual vs. shared)
Dyadic Appraisal	Definition: The dyad's shared understanding the NDD and its impact Examples of Dyadic Appraisal: • Dyad's shared understanding of NDD and symptoms (cognitive, physical, behavioral changes), including the attribution of symptoms to NDD, causes, expected progression • Dyad's shared understanding of impact of NDD on daily living and future • Dyad's negotiation of NDD care preferences (e.g., ways of managing NDD symptoms, navigating medical visits and decision-making, desired information, and resources) • Dyadic experience of stressors (e.g., emotional reactions to NDD and related stressors) • Illness ownership (e.g., attribution of stressors as individual vs. shared)
Individual Coping Strategies	Definition: Skills that dyad members can enact individually to effectively manage difficult emotions and cope with stressors Adaptive Individual Coping: • Internal strategies (e.g., mindfulness, acceptance, optimism, gratitude, self-efficacy) • Behavioral strategies (e.g., soliciting social support, engaging in self-care, building mastery of ways of navigating challenges and cultivating new skills)
Dyadic Coping strategies	Definition: Skills that dyad members can enact together to manage difficult emotions and cope adaptively with stressors Examples of Adaptive Dyadic Coping: • Collaborative problem solving and delegation of tasks amid individual challenges • Open communication about individual thoughts, emotions, and stressors
Dyadic Biopsychosocial Adjustment	Definition: Individual physical and mental health and relational functioning following NDD diagnosis Examples of Dyadic Adjustment: • Severity and/or chronicity of emotional distress • Individual physical health and quality of life • Dyadic relationship satisfaction, communication, and intimacy
Symptom Progression and Transition Points	Definition: Changes in stage of illness or symptoms that can impact dyad's care needs and adjustment to NDD Examples of Symptom Progression and Transition Points: • Person with NDD's fluctuating or declining abilities (e.g., changes in insight) • Decline in abilities leading to changes in roles and responsibilities (e.g., driving, cooking, working, and other activities of daily living)

Table 2.

Case examples of transdiagnostic interventions for dyads early after NDD diagnoses

Component	Case 1	Case 2
Contextual Factors	Spousal dyads comprising of a cisgendered White female partner (age 67) recently diagnosed with AD and a cisgendered White female partner (age 64). Both partners reported good premorbid health and relationship functioning prior to diagnosis and experience the diagnosis as "overwhelming."	Parent-child dyad comprising of a White Hispanic father (age 72) diagnosed with PD and White Hispanic daughter (age 45). Person with PD had a medical history significant for Type II diabetes prior to PD onset. Dyad's relationship was strained due to substantial life stressors (recent loss of spouse/mother one year prior to diagnosis).
Early Symptoms	Prominent AD symptoms include memory loss, changes in attentional abilities, and some changes in emotional expression (empathy, humor).	Prominent PD symptoms include resting tremors, difficulty moving/ walking (speed, transitions), sleep disturbance, changes in speech (speed, inflection), decreased energy and motivation for daily activities.
Significant Early Stressors	Dyad's most substantial stressors include decisions about person with AD's ability to safely drive, different understandings of impact of AD on long-term plans (e.g., retirement, advanced care plans), and different attributions of behaviors to symptoms or person (e.g., forgetting location of things, changes in empathic responding from person with AD during difficult conversations).	Dyad's most substantial stressors include person with PD's depression symptoms (e.g., low motivation, fatigue, hopelessness), communicating about person with PD's medical care and health behaviors (diet, physical activity, sleep), transition to role as care-partners, communicating amid negative/overwhelming emotions (grief, anger, anxiety).
Clinician Tailoring of Content for Dyad: To address Illness-related factors and External Resources, Symptom Progression and Transition Points	Presentation of skills in multiple modalities (e.g., in-session, online with audio, video, and written information), use of accessible language Emphasis on home practice of skills and tailoring to address dyads' barriers to skills use (e.g., time, setting reminders to minimize impact of memory deficits, practicing skills together) Identification of resources for dyad to navigate transitions to higher levels of care	Presentation of skills in multiple modalities (e.g., in-session, online with audio, video, and written information), use of accessible language Emphasis on home practice of skills and tailoring to address dyads' barriers to skills use (e.g., planning time for each person to practice skills separately and together Identification of support groups and activities for person with PD and care-partner; resources for dyad to navigate transitions to higher level of care.
Dyadic Biopsychosocial Outcomes: Primary Intervention Targets (based on dyad's prominent stressors)	• AD symptoms (e.g., cognitive functioning) • Relationship functioning (conflict, intimacy) • Quality of life	• Self-care and health management behaviors (e.g., physical activity, diet, stress management) • Relationship functioning (conflict, intimacy) • Quality of life

Table 3.

Proposed session content of early dyadic interventions for NDDs

	Case 1	**Case 2**
General Session 1: Individual and Dyadic Appraisal of NDD Diagnosis and Stressors	Education focused on: Common early symptoms, relationship changes, and emotional reactions to changes Skills focused on: Increasing awareness of diagnosis, symptoms, and prognosis for dyad. Increase present moment focus, non-judgmental awareness of symptoms and changes, reduce overwhelming emotions, and set the stage for more effective communication Examples of skills: deep breathing, mindfulness, staying within the 24-hour block, mindfulness meditation)	
	Case 1	**Case 2**
General Session 2: Coping with Uncertainty	Education focused on: Ways to evaluate current abilities and needs for daily tasks (e.g., cooking, driving, working). Common trajectory of NDD and ways of identifying and navigating "transition points" with changing needs Skills focused on: Coping with conflicting thoughts/ feelings, reduce focus on worry-thoughts, understand active vs. emotional coping. Examples of skills: Dialectical thinking, deciding between acceptance and change, problem-solving coping, radical acceptance	
	Case 1	**Case 2**
General Session 3: Content and Skills to Navigate Interpersonal Relationships and Engage Support Resources	Education focused on: Ways to identify historic and current interpersonal communication dynamics and positive communication behaviors (e.g., speaker-listener skills, empathic responding, perspective taking) Skills focused on: building on dyad's strengths and proactively plan for difficult conversations, collaboratively navigate challenges, and make decisions for the future Examples of skills: interpersonal effectiveness (clarifying goals, dyadic coping)	
	Case 1	**Case 2**
Additional Session Topics: Content and Skills tailored to dyad's most prominent early stressors (3-4 additional sessions)	**Session 4. Dyadic coping for adjusting to symptoms and adhering to medical recommendations** Education focused on: safety considerations for daily activities (driving, cooking, working) and modified ways of participating; examples of dyadic coping amid changes Examples of skills: adjusting values and priorities to current functioning, modified pleasant activities based on person with AD's abilities, positive psychology skills (humor, gratitude, optimism) **Session 5. Preparing for transitions and future needs** Education on identifying "transition points" and communicating about care and support needs. Using skills (mindfulness, dialectics) to cope ahead of future challenges. Examples of skills: Dialectical thinking to identify ways things have changed and stayed the same in dyads' relationship and roles, using mindfulness and dialectics to preserve autonomy and relationships throughout AD progression **Session 6. Meaning making** Education on ways of using skills (e.g., mindfulness, dialectics) to understand the illness experience and transition to care-partners; examples of making meaning in the midst of a terminal diagnosis. Examples of skills: Exercises to promote individual and interpersonal/dyadic valued living (e.g., "bucket list"), radical acceptance, using dialectics to grieve losses and move forward	**Session 4. Dyadic coping for adjusting to symptoms and adhering to medical recommendations** Education on strategies to adhere to self-care and medical provider recommendations for care; modified ways of participating in daily activities (cooking, physical activity); examples of dyadic coping amid changes Examples of skills: goal setting for adherence to medical regimens; modified pleasant activities based on person with PD's abilities; positive psychology skills (humor, gratitude, optimism) **Session 5. Fear of worsening symptoms and grieving losses** Education on fear/worry, observing difficult emotions, and deciding between acceptance and change strategies; communicating about fear and worry as a dyad. Examples of skills: Mindfulness and chain analysis to identify thoughts/feelings of fear and worry and associated behaviors (e.g., rumination, planning); dialectical thinking to identify thoughts/feelings to accept and skills to practice; dyadic coping about difficult thoughts/emotions and asking for support. **Session 6. Engaging in positive activities** Education on benefits of behavioral activation and social support resources (e.g., weekly activities, support groups, engaging social network). Examples of skills: Daily goals for pleasant activities tailored to person with PD's abilities; goals for self-care behaviors; self and other-compassion practices to increase motivation.