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Design and Implementation of a Clinical Science Specialty Clinic for Adults with Neurological Disorders and Their Caregivers

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Abstract

Mental health problems are common for persons with neurological disorders (PWNDs) and their caregivers (CGs) but often are not adequately treated. Despite this growing need, the training of clinical psychologists typically does not include coursework or practicum experience working with these populations. To address this, a team of faculty, supervisors, and doctoral students in UC Berkeley's Clinical Science program undertook a year-long process that consisted of building a training curriculum that integrated coursework and consultation with visiting experts; providing supervised practicum training with PWNDs and CGs and evaluating training and clinical outcomes. We hoped to prepare students to train other mental health professionals to work with these populations in the future. In this article, we describe the Specialty Clinic with special attention given to the training provided, challenges faced and solutions found, clinic operations and logistics, and lessons learned. We also review key clinical issues and report key indicators of client outcomes. Finally, we evaluate the success of the Specialty Clinic and offer recommendations for others interested in providing these kinds of much needed training and clinical services in this important area.

Keywords

clinical psychology; neuropsychology; clinical science training; neurological disorders; caregiving; psychological treatment

Neurological disorders and mental health

Neurological disorders (NDs) constitute a major public health challenge worldwide, with nearly 12 million cases in the United States alone (Borlongan et al., 2013). Recent estimates

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of the costs for treatment and care for people with these adult-onset NDs (PWNDs) exceed \$500 billion annually (Gooch et al., 2017). Because PWNDs may need help with activities of daily living, family caregivers (CGs) are often called upon to provide critically needed assistance. Providing care for a loved one is an important and meaningful part of family life (Abdollahpour et al., 2017), but the associated stress, burden, and responsibilities often result in CGs' experiencing profound declines in mental and physical health (Schulz et al., 1995). CGs and PWNDs risk falling into a downward spiral in which mental health decline in CGs can compromise their ability to provide high quality care, in turn leading to increased PWND mortality (Lwi et al., 2017). These issues are likely to increase markedly, driven by a rapidly aging population worldwide (Ortman et al., 2014).

Persons with neurological disorders and neuropsychiatric symptoms

The dramatic changes in physical and cognitive functioning that occur in PWNDs typically command the attention of health care providers and become the initial focus for treatment. Many PWNDs receive effective rehabilitative treatment for language (e.g., via Speech Therapy) and movement problems. In cases of neurodegenerative diseases (e.g., Alzheimer's disease and other dementias), rehabilitative treatments may offer short-term improvement in language and motor functioning. These treatments are typically provided in outpatient rehabilitation or hospital settings that do not focus on mental health, leaving the profound psychological distress experienced by many PWNDs untreated (Baquero & Martín, 2015; Shdo et al., 2020; Kneebone & Dunmore, 2000).

Caregivers

Family members and friends of PWNDs often become deeply involved in caregiving, assisting PWNDs with activities of daily living (Moore et al., 2001). The primary CG for a PWND is typically a spouse, partner, adult child, or close friend (Schulz & Czaja, 2018; Family Caregiver Alliance, 2016). CGs transport PWNDs to medical appointments, pick up prescriptions, and carry out in-home rehabilitative activities. Further, as the PWND's disease progresses, the CG's responsibilities often grow to include roles that the PWND used to perform (e.g., managing family finances, cooking, making household repairs), while still fulfilling their own responsibilities (Tooth et al., 2005). These commitments, combined with reduced contact and support from friends and family create high levels of burden and stress (Robison et al., 2009). Unsurprisingly, as is the case with PWNDs, caregivers frequently develop psychiatric symptoms including depression and anxiety (Berg et al., 2005). With attention focused on PWNDs in homes, clinics, and research settings, mental health symptoms in CGs can go unnoticed and untreated. This situation may be exacerbated by CGs not recognizing or prioritizing their own health, as well as financial and time constraints (Brodaty & Donkin, 2009).

A role for clinical psychologists

Traditionally, clinical psychologists are trained to address disorders such as depression and anxiety, but do not receive specialized training in providing psychological treatment for PWNDs or their CGs. Two exceptions to this are neuropsychologists (who provide

assessments for PWNDs) and health and rehabilitation psychologists (who often function as a part of comprehensive care teams). This lack of specialized training is reflected in typical clinical psychology curricula, which often do not include coursework or practicum experiences related to NDs or caregiving. One exception to this is the Pike's Peak model which involves training geropsychologists using a competencies-based approach to working with older adults (Knight, 2009). This method however, is not widely available at general psychology training programs. Moreover, unless special outreach efforts are launched, clinical psychology graduate students are unlikely to encounter these issues in university-based training clinics. For example, when we queried current and past staff and leadership of the UC Berkeley Psychology Clinic, they were unable to recall a single instance of a PWND, CG, or PWND-CG dyad being provided with psychotherapy over the past decade. The one exception to this, was one prior Specialty Clinic devoted to couples dealing with dementia (Levenson, 2014).

This lack of training is unfortunate because it is easy to envision clinical psychologists providing evidence-based psychological interventions to PWNDs and CGs. For PWNDs, the time around initial diagnosis can be emotionally difficult as present and future declines in their functional abilities necessitate significant lifestyle adjustments. For those who experience a sudden onset of ND, such as with stroke or TBI, the abrupt loss of language, motor, or cognitive functions has immediate consequences that require not only prompt medical attention, but also significant social, emotional, and behavioral support (e.g., Gouick & Gentleman, 2004) that clinical psychologists are well positioned to provide. For CGs, there are huge unmet psychological issues related to the profound and often sudden changes that occur in couple and family relationships as well as the strain of accommodating necessary lifestyle adjustments for PWNDs (Etters et al., 2008). These issues could be effectively addressed by clinical psychologists who are trained in evidence-based interventions with couples and families. These kinds of interventions are not part of standard treatment protocols for PWNDs and CGs.

A great deal of attention has been given to developing treatments that address burden and strain in dementia CGs many have shown promise in initial efficacy trials (e.g., Dowling et al., 2014). However, it has been difficult to scale them into successful real-world effectiveness trials and disseminate them into large-scale community use (Gitlin et al., 2015; Schulz et al., 2005). A recent review of CG interventions (Butler et al., 2020) that included almost 600 unique studies concluded that there were only three interventions that showed even "low-strength" evidence for efficacy: the multicomponent REACH II program (Resources for Enhancing Alzheimer's Caregiver Health; Belle et al., 2006), ACCESS (Alzheimer's disease Coordinated Care for San Diego Seniors; Chodosh, 2015), and UCSF Care - ecosystem (Possin et al., 2019). These interventions address a number of issues confronted by CGs ranging from providing practical help with activities of daily living (e.g., toileting and hygiene), managing difficult patient behaviors (e.g., wandering, agitation), and navigating complex healthcare systems. Although reducing CG's psychological distress is certainly a goal of these interventions, they do not incorporate the personalized, symptom-focused, multi-session approach that characterizes evidence-based psychotherapies delivered by well-trained clinical psychologists. Integration of such an approach into CG interventions may improve outcomes.

Although there is a compelling argument for greater involvement of clinical psychologists in dealing with the mental health problems experienced by PWNDs and CGs, there are significant barriers that need to be scaled. There are important differences in etiology, course, and impact of different NDs (e.g., stroke vs. degenerative disease). Some behavioral changes that occur with NDs are malleable while others are irreversible; some changes are stable, while others are likely to change over time; and disease trajectories change in ways that are both predictable and unpredictable (Acevedo & Loewenstein, 2007; Young et al., 2018). This landscape is less familiar for many clinical psychologists compared with health and rehabilitation psychologists, who more often have experiences working with NDs as part of comprehensive care teams. Considering all of these factors, there is a compelling argument to be made for additional training and involvement of clinical psychologists in caring for PWNDs and CGs.

Creating a Specialty Clinic devoted to PWNDs and CGs at UC Berkeley

Given that students in most clinical science doctoral programs receive little or no academic training in treating neuropsychiatric symptoms and psychiatric symptoms in NDs and CGs, Dr. Dronkers and Dr. Levenson identified a critical need to develop training among doctoral students to address these issues. A Specialty Clinic training model (Levenson, 2014) within the existing UC Berkeley Psychology Clinic was selected. This model includes an academic seminar, providing clinical services under supervision, meetings with local and national experts, and evaluating clinical and training outcomes. Students learn how to identify an area of unmet need for mental health services, help plan a seminar to obtain critical knowledge about relevant theory and research, adapt clinic procedures to accommodate the target population and intervention, design and implement a research plan for evaluating treatment outcomes, conduct outreach efforts to recruit clients, and document their training, clinical experiences, and research findings. At the heart of this model is the belief that the training of Ph.D.-level clinical scientists must go beyond learning to deliver existing manualized treatments to traditional clients. Rather, students should be trained to embrace unknowable challenges by identifying areas of need, reaching out to underserved populations, harnessing disparate resources, developing new forms of assessment and treatment, instituting rigorous evaluations, and disseminating their work. A Specialty Clinic that addressed the unmet mental health needs of PWNDs and their CGs was an ideal match for this model.

Four student clinicians participated in the specialty clinic which was led by Dr. Dronkers, Dr. Levenson, and Ms. Tang. Two students had prior experience working with PWNDs and CGs in research but no prior clinical experience with these populations, and the other two had no prior experience with these populations. The four graduate students distributed fliers to local clinics, hospitals, and professionals. Working with the faculty, they assembled client measures, screening forms, and seminar readings, as well as a group of local content experts to meet with the class.

Training model

The Specialty Clinic had three goals: (a) to address a major gap in providing psychological services to PWNDs (e.g. dementia, stroke, TBI) and their CGs; (b) to train students to

treat the mental health problems common to these populations; and (c) to prepare a cohort of students to help train current and future clinical science students to work with these populations and to create Specialty Clinics at other institutions after graduation.

Weekly seminar and case conference.

The clinic team met for a two-hour seminar and case conference once per week. Each meeting included: (a) discussions of scientific literature on a topic of importance for working with PWNDs and CGs; (b) meetings with guest speakers; (c) clinical case conferences; (d) refining administrative procedures for recruitment, progress monitoring, and population-specific interventions; and/or (e) evaluating clinical outcomes (See online supplemental material). During the term, trainees led 4–6 case conference presentations and 4–6 didactic seminars.

The seminar began with foundational readings and presentations on the classification and etiology of dementia, stroke, and TBI. Sessions on the societal impact of these diseases included visits by Richard Schulz (University of Pittsburgh), who presented his research on CG burden and treatment and Jennifer Merrilees (UCSF), who presented a multidimensional treatment approach for these populations used in the UCSF Care-ecosystem intervention (Possin et al., 2019).

Next, many weeks were devoted to evaluating the intervention literature. These were augmented by invaluable contributions made by visitors to the seminar including Dolores Gallagher Thompson (Stanford University), Laura Gitlin (Drexel University), Joan Monin (Yale University), and Maureen Kelly (UC Berkeley). The therapeutic utility of psychoeducation was interwoven throughout the seminar; every case seen in the clinic benefited from learning more about the ND that either they themselves or their loved one was living with. Cultural considerations – such as familial responsibility, independence versus interdependence, intergenerational trauma, views concerning the ideal self, and beliefs about emotional expression – were woven into scientific and clinical discussions throughout the year. A talk by seminar faculty member NT, who has extensive clinical experience working with members of different cultural, national, and ethnic groups, served as a cornerstone for integrating these issues.

Student-led seminars focused on specialized interventions (e.g. REACH II; Belle et al., 2006), as well as psychotherapy interventions that have been applied to PWNDs and their CGs (e.g. Cognitive Behavioral Therapy [CBT] and Acceptance and Commitment Therapy [ACT]; Losada et al., 2015). Each week, part of the seminar was devoted to a clinical case conference in which students presented current cases and received feedback and support from seminar faculty.

Supervision.

Each student had a weekly, individual supervision session with a licensed mental health professional (doctorate or masters-level). Supervisors were selected for their expertise in providing evidence-based care to adults with psychopathology. Supervision sessions adhered to the UC Berkeley clinical science program's standards and included a review of cases, review of video/audio tapes from sessions, teaching of skills via role-plays between student

and supervisor, and collaborative planning for future therapy sessions. Supervisors wrote evaluations of student progress at the end of both semesters.

Bridging the gap: Adapting a standard training clinic to serve PWNDs and their CGs

Mounting a Specialty Clinic in one year is a complex undertaking that is fraught with challenges. This section outlines several of the key obstacles we encountered and how they were addressed.

Recruitment.

Despite substantial untreated psychological distress in these populations and endorsements of the need for these services by local professionals, the Specialty Clinic initially received relatively few calls from people seeking these services. This may have resulted for several reasons. CGs often prioritize the care of the PWND and are reluctant to allocate time and financial resources for their own self-care. As the burdens of caregiving mount over time, they may become increasingly overwhelmed and distressed and lack the time and energy to seek out help for themselves. For PWNDs, medical appointments may be prioritized over those related to alleviating psychological distress.

Addressing these issues required additional outreach beyond the Psychology Clinic's usual efforts and took several months. A new flyer was created using tailored language based on feedback from CGs, PWNDs, and leaders from other PWND and CG organizations. The flyer was distributed by CG organizations and posted in public spaces, and students manned tables and presented at senior centers and built relationships with social workers, case managers, and staff. The students and faculty also contacted colleagues at local institutions that provide services to PWNDs, including a hospital and an academic medical center. Based on these experiences, we recommend beginning recruitment at least two months before opening this kind of Specialty Clinic, posting flyers and advertising services at community and senior centers, and collaborating with in-home providers for PWNDs and CGs.

Accessibility and telehealth.

Traveling to weekly therapy sessions may be difficult for PWNDs and CGs in the best of times. Many individuals in these populations have problems with mobility, transportation, and, in the case of CGs, difficulty leaving a PWND alone at home. To address these barriers, the Specialty Clinic team spearheaded the implementation of telehealth services for the larger UC Berkeley Psychology Clinic. Activities to establish these services began in November 2019 working with the Psychology Clinic Director and the campus IT and security staff. The first remote therapy session in the Specialty Clinic was conducted in March 2020. Crucially, these telehealth protocols were approved days before UC Berkeley closed due to COVID-19, and enabled the Specialty Clinic to continue remotely.

Conducting teletherapy in the Specialty Clinic required technological proficiency beyond the skill levels of some of our clients. To increase accessibility, students offered free 30–45 minute tutorial sessions to guide clients in downloading the HIPAA-compliant Zoom

software, joining Zoom meetings, enabling audio and video, and having a brief practice session. Students communicated clear contingency plans should technical issues arise during sessions. The overwhelmingly positive experiences using teletherapy with the range of clients seen in the Specialty Clinic (and in the rest of the Psychology Clinic) established this as a viable option to supplement in-person therapy in the future.

Financial considerations.

NDs create increased financial burden for families due to lost income for the PWND and CG, medical costs, and the need for additional professional care. The Specialty Clinic used a sliding scale for services based on annual income, the number of dependents in the household, and the burden of medical and caregiving costs. This helped several clients avoid the critical choice between mental health care and other medical and support services. Of note, the UC Berkeley Psychology Clinic does not accept insurance, including medicare or medicaid. Being able to accept these kinds of payments will be especially important for future clinics if they are unable to offer a sliding fee scale.

Operation of the Specialty Clinic

Case flow.

Interested individuals were required to call the main clinic phone number, as their first point of contact. A student clinician completed a 45-minute phone screen to assess the match between the individual's needs and the clinic's services. To be included in this Specialty Clinic, individuals had to be diagnosed with a ND or serve as a primary caregiver for a PWND. Although the clinic aimed to serve individuals with a range of NDs that impact cognitive, emotional, and motor systems, all cases that sought services in our clinic had primary neurocognitive deficits. Per the standard clinical procedures in the UC Berkeley Psychology Clinic, individuals with primary substance use problems, high risk for suicide or violence, or current legal involvement were excluded. A total of 20 individuals completed a phone screen, four of which did not meet the clinic criteria or chose to discontinue. Sixteen individuals seeking treatment within the purview of the Specialty Clinic completed an in-person 90-minute intake session with a student clinician to assess fit further. Twelve individuals were determined to be a fit for the Specialty Clinic and decided to begin treatment. Four individuals decided to not initiate treatment after the intake appointment and the student clinicians referred them to alternative local services. The clinic had the capacity to serve PWND/CG dyads via individual and dyadic treatment, and advertised this opportunity throughout recruitment efforts, but no dyads were recruited into the Specialty Clinic (i.e., none of the 12 clients had a PWND or CG that was also receiving care in our clinic).

Treatment planning and implementation.

The Specialty Clinic set out to implement empirically-supported treatments that targeted psychological distress suffered by CGs and PWNDs. In reviewing the literature, a number of evidence-based treatments were identified that broadly aimed at improving the quality of life and well-being of these populations. However, few of these treatments had been shown effective in large scale trials (Gitlin et al., 2015). Empirical evidence was strongest

for REACH II, an intensive multifaceted intervention (Butler et al., 2020). REACH II offers psychoeducation, group discussion, in-home and phone support, and CG feedback. Evidence suggests it reduces CG depression at 6 months (Belle et al., 2006). Several components of the REACH II suite, such as phone support and group therapy, were beyond the capacity of our Specialty Clinic, which focused primarily on one-on-one face-to-face talk therapy.

Given the general lack of evidence around other interventions for these populations and the incompatibility between the clinic's structure and that of the REACH II intervention, the Specialty Clinic team adopted a treatment approach similar to the overarching UC Berkeley Psychology Clinic's approach based on individualized case formulation. Here, interventions from a wide range of evidence-based modalities, including CBT, ACT, Dialectical Behavioral Therapy (DBT) and psychodynamic strategies, were integrated to provide personalized treatment to clients. The case formulation approach is appropriate for complex cases such as PWNDs and CGs, because it provides the flexibility to implement interventions that incorporate empirically-supported treatments (Persons, 2012). For example, when clients presented with more general psychological challenges (i.e., depression and anxiety), the team could draw upon existing treatments in this area, guided by drawing upon existing expertise in the UC Berkeley Psychology Clinic. When clients presented with concerns more specific to caregiving and NDs, the elements of REACH II could be implemented, such as PWND-specific psychoeducation.

Case formulations for Specialty Clinic clients were further anchored in a transdiagnostic framework that identified patterns of thoughts, feelings, and behaviors that support and maintain common psychological disorders. Rather than focusing on the level of the psychological disorder, the transdiagnostic approach focused on the underlying psychological processes, such as avoidance, rumination, and/or perfectionism, which occur in many clinical disorders. Typically, case formulations include existing schemas (e.g., the belief that others are judgmental), triggers (e.g., family and friends criticizing caregiving choices), and mechanisms associated with a given client's symptoms (e.g., having high expectations for oneself; Frank & Davidson, 2014). In consultation with their clinical supervisors, students first considered adopting existing evidence-based treatments such as CBT (Beck & Fernandez, 1998), DBT (Lynch et al., 2016), ACT (Hayes et al., 2012), and Brief Psychodynamic Therapy (Gallagher-Thompson & Steffen, 1994) that could be utilized to best address their clients' issues. Existing mental health interventions for PWNDs and their CGs (e.g., REACH II) were also considered. All treatment plans were continuously monitored and modified as needed in response to transitions in clients' case formulations.

Treatment evaluation.

Because there is no evidence base for applying a transdiagnostic case formulation approach to these specific populations, quantitatively tracking client responses to treatment was of utmost importance. Our treatment evaluation included measures used with all adult clients at the UC Berkeley Psychology Clinic. This included the Depression Anxiety and Stress Scales (DASS-21; Lovibond & Lovibond, 1995) and the World Health Organization Disability Assessment Scale (Üstün et al., 2010), which were administered on a weekly basis. The DASS-21 is a 21 item, self-report questionnaire that measures depression (e.g., "I felt

downhearted and blue”), anxiety (e.g., “I felt that I was close to panic”), and stress (e.g., “I felt I was rather touchy,” (Lovibond & Lovibond, 1995). Scores are reported on a Likert scale from 0 (“did not apply to me at all”) to 3 (“applied to me much or most of the time”). Although the Geriatric Depression Scale (Yesavage et al., 1988) and the Geriatric Anxiety Scale (Segal et al., 2010) were appropriate measures for some of our clients, we chose to use the DASS-21 for all clients to facilitate between-client comparisons. The WHODAS 2.0 is a 12-item self-report measure of disability that includes a range of functional domains including cognitive, mobility, self-care, getting along with others, life activities, and participation (e.g., “In the past 30 days, how much have you had difficulty with standing for long periods such as 30 minutes?”; Üstün et al., 2010). Responses options are based on a 0 (none) to 4 (extreme/cannot do) Likert scale. Total scores are converted to a summary score ranging from 0 (no disability) to 100 (full disability).

We augmented these measures with others that assessed issues of particular relevance for CGs and PWNDs. To measure CG burden, the Zarit Burden Interview was administered to all CGs (Zarit et al., 1985). The Zarit Burden Interview is a 22-item self-report questionnaire that measures CG burden (e.g., “do you feel strained when you’re around your relative?”). Scores range from 0 (“did not apply to me at all”) to 4 (“applied to me very much or most of the time”). Total scores range from 0–88.

Regarding frequency of administration, the DASS-21 was collected prior to the first therapy session to establish baseline symptom levels and then was collected weekly throughout treatment. The WHODAS and Zarit Burden Interview were both delivered at baseline as well as throughout treatment, however the frequency that these measures were given varied based on supervisor guidance.

In addition to progress notes, case formulation hypotheses and treatment recommendations were discussed on a weekly basis during supervision sessions and in the Specialty Clinic seminar. Case formulation reports were written after the fourth session for each client. These formulations outlined presenting problems, psychosocial and medical history, clinician hypotheses of psychological mechanisms, and the treatment plan (Persons, 2012; Frank & Davidson, 2014).

Treatment observations and outcomes.

The UC Berkeley Institutional Review Board indicated that our assessment of treatment and outcomes was exempt from formal review. Twelve clients were seen in the Specialty Clinic over the course of two semesters (Table 1). Clients were evenly distributed across the four trainees. There were seven CG clients and three PWND clients. All CG clients were women and three out of four PWND clients were men. Five of the CG clients cared for persons with Alzheimer’s Disease and two cared for individuals who had strokes. The CG clients were aged between 44 and 79 while the PWND clients were aged between 40 and 78. The gender and age demographics of the clients in our Specialty Clinic parallel trends described in the literature. That is, many more women than men fulfill the responsibilities of caregiving for PWNDs, and adult PWNDs and their CGs span a large age range from the fourth to eighth decades of life and beyond (Schulz et al., 2019). Six CGs identified as White and one as Asian. All three PWNDs had TBIs. The clients did not report the clinically diagnosed

severity level, however, cognitive symptoms had persisted for several years, indicating that the severity was likely in the moderate range. Two PWNDs identified as White and one as Asian. The ethnic makeup of the clients was similar to that usually seen in the Psychology Clinic. The lack of diversity reflects a program-wide need for additional concerted outreach to Black, Indigenous, and People of Color (BIPOC) communities.

Clinical observations

Common psychological experiences and symptoms.

A number of common psychological experiences and symptoms were identified through the weekly team meetings. CGs were likely to experience anger, guilt, and a combination of grief and grief avoidance. Anger was typically associated with frustration regarding PWND symptoms. CGs often misinterpreted PWNDs' disease-related behaviors, such that deficits in functioning were interpreted as willful and intentional on the part of the PWND. Guilt was often associated with caregiving choices, such as not spending enough time with the PWND or ruminating about whether they were "good enough" as CGs. Grief was common and frequently included sadness and feelings of loss associated with the loss of the PWND's personhood. Avoiding grief was common among CGs and frequently associated with their becoming hyper-responsible for patient care. For example, CGs often devoted themselves to taking on additional caregiving responsibilities in order to avoid processing their sense of loss.

Like CGs, PWNDs seen in the clinic reported difficulties with anger, guilt, and grief. However, underlying dynamics and mechanisms of these difficulties were noticeably different in PWNDs. For example, for PWNDs, anger was frequently self-directed, focused on the discrepancies between their current cognitive abilities as compared to their abilities prior to the onset of their ND. All PWNDs reported feeling guilt for not being able to carry out fully their responsibilities to loved ones, such as not being able to work or not being able to be emotionally present and supportive. All PWNDs shared grief around their neurocognitive difficulties and expressed feelings of deep sorrow for being unable to return fully to prior levels of functioning.

Common treatments.

Out of the personalized approach to intervention selection described above in the "Treatment selection and evaluation" section, patterns emerged through team discussions, linking evidence-based treatments with transdiagnostic symptoms and mechanisms. Although our sample size was not sufficient for formal quantitative assessment of these patterns, qualitative description may still prove useful for future clinics and could serve as a starting point for deeper empirical investigation. Psychoeducation about NDs (Beinart et al., 2012) and cognitive restructuring (Beck & Fernandez, 1998) were often used to address instances of CG and PWND anger, as well as CG misinterpretations of PWND behaviors. For guilt, grief-related symptoms, and lack of acceptance of the disease, mindfulness and acceptance skills (Márquez-González et al., 2010) were selected. Over-responsibility was addressed with values-based decision making (Frank & Davidson, 2014). Behavioral activation and pleasant activity scheduling was used to address stress and disease related anxiety (Orgeta et

al, 2019). Building insight through interpretation of transference, a psychodynamic approach (Henry et al., 1994), was useful for improving interpersonal skills (e.g., assertiveness and social rapport building) that had been negatively impacted by client NDs and associated difficulties. These improved interpersonal skills could then be used by clients to facilitate social network development and improve quality of life.

Quantitative treatment outcomes.

One approach to evaluating client outcomes was to examine trajectories in depression, anxiety, and stress scores across the course of treatment, measured via the DASS-21 (Lovibond & Lovibond 1995). Although data were also collected regarding caregiver burden and functional impairment, we did not examine group-level trends in these measures because they were administered infrequently and were primarily for use in individual treatment planning and case formulation. On average, CG clients reported decreases in anxiety and stress symptoms over the course of treatment; in contrast, depression symptoms did not improve (Table 2a–c). As was the case with CG clients, PWND clients reported decreases in anxiety symptoms. However, in contrast to CGs, PWNDs reported very little change in stress symptoms and reported increases in depression symptoms (Table 2a–c). In addition to these changes in symptoms at the group level, three symptom trajectories emerged when looking at session-by-session data for individual clients. In the first pattern (2 CG clients), there was improvement in all symptom domains and all symptoms remained low until the end of treatment. In the second pattern (3 CG clients), there was improvement in anxiety and stress symptoms but no improvement in depression symptoms. In the third pattern (2 CG clients, 3 PWND clients), there was essentially no change in any domains across the course of treatment. Although the benefits of individual psychotherapy on psychological distress for CGs and PWNDs may appear modest using these measures, two important factors should be considered. First, the last two months of sessions in the specialty clinic took place during the COVID-19 pandemic, a period in which clients were required to “shelter-in-place.” In addition to a generalized increase in worry and stress regarding health and safety, the collective structural changes to society produced large strains on clients’ resources and support systems. This undoubtedly impacted clients’ symptoms. Second, most NDs represented in the cases were neurodegenerative. Reflecting this, mental health symptoms for CGs and PWNDs (e.g., depression, anxiety, stress, burden) often increase as neurodegeneration progresses (Schulz et al., 2019). Therefore, in addition to improvement in anxiety and stress symptoms for many CGs, the stable symptom trajectories seen in some cases might suggest that the treatment prevented their symptoms from worsening, as might be expected amidst the compounding stressors of NDs and a global pandemic. Determining whether these stable symptom trajectories actually represent benefits from the intervention would require comparison with a control group (e.g., treatment as usual or waiting list), which we did not have.

Qualitative treatment outcomes.

Looking back over our experience in the Specialty Clinic, we observed a number of patterns that showed consistency across clients. Although these qualitative observations are not based on quantitative measures and formal statistical analyses, we hope that they will still be useful for others who are considering or already providing psychotherapeutic interventions with

CGs and PWNDs. They may also point to useful areas to include when planning future assessments and treatment evaluations. In particular, we hope that our speculations about processes leading to client change can be evaluated formally as mediating mechanisms in future studies.

Psychoeducation appeared to be helpful for treating CG anger and misinterpretation of PWND symptoms, especially for CGs who had less understanding of the ND symptomatology and progression. Cognitive restructuring was effective for addressing anger and guilt in CGs that reported relatively low burden (i.e., external stressors), potentially due to these CGs having relatively higher levels of cognitive and emotional resources available for internal structural change. For CGs experiencing relatively high levels of burden, cognitive restructuring proved less successful, potentially due to persistent external stressors not addressed via cognitive restructuring or a diminished ability to engage effectively in cognitive restructuring due to depleted cognitive resources. Acceptance-based strategies appeared to be effective in addressing CG anger (e.g., accepting that the PWND's behavior will not change) and guilt (e.g., acknowledging that "I am giving as much time as I possibly can to my caregiving tasks, and it would be impossible to give more"). Acceptance-based strategies seemed to be less effective when CGs were avoiding acknowledging the disease and disease-related behaviors as a way of controlling grief and sense of loss.

For PWNDs, psychoeducation appeared to help decrease shame and guilt around symptoms. For those who had previously received psychoeducation, additional psychoeducation seemed particularly effective when combined with acceptance-based interventions. This may have worked by combining clients' intellectual understanding of the impact of the ND on oneself with acceptance of its impact on thoughts, feelings, and behaviors. Cognitive restructuring strategies appeared less effective with PWNDs compared to CGs, perhaps due to diminished cognitive resources.

For both CGs and PWNDs, transference strategies – i.e., acknowledging and discussing "in the room" manifestations of the mechanisms perpetuating the psychological distress – appeared effective when addressing assertiveness and broad interpersonal skills, as reflected by a gradual increase in self-esteem. Clients reported that improvements that began in therapy sessions generalized to external relationships, thereby indicating advancement towards the overarching goal of developing a robust social network and support system.

Attrition.

Attrition rates are important indicators of treatment success because of the critical role that continuity of care plays in promoting effective treatment. Studies of psychotherapy indicate that 11 to 13 sessions are typically needed for most clients to experience symptom alleviation, or to be considered "recovered" (Barrett et al., 2008). Despite this recommended "dose" of therapy, studies also show that approximately fifty percent of clients discontinue psychotherapy treatment after just two sessions and that CG interventions have particularly high levels of attrition (Davis et al., 2006). As such, ensuring low attrition was of great importance to the Specialty Clinic team.

In our Specialty Clinic, attrition rates were quite low. Only two out of twelve (16.7%) clients who began treatment dropped out after one or two sessions. The remaining ten clients (83.3%) stayed for between seven and 28 sessions. One client terminated unexpectedly after 10 sessions. All other clients who terminated before the clinic closure did so in collaboration with their clinician and in a manner consistent with treatment progress. The rest of the clients continued with treatment for the maximum amount of time before the clinic ended. The Specialty Clinic's low attrition rate is a positive indicator. It is consistent with many clients reporting that they valued their treatment, and it underscores the need for and value of providing mental health services that address the psychological needs of PWNDs and CGs.

Evaluating the Specialty Clinic experience

The Specialty Clinic was founded on three primary goals. The first goal was to address a major gap in providing psychological health services to PWNDs and their CGs. Despite the high rates of psychological distress in the populations of interest, the number of callers expressing interest in the Specialty Clinic was lower than anticipated. A large additional outreach effort was necessary to increase the number of clients. Momentum built as the breadth of community and professional recruitment contacts developed, but we struggled to keep all student caseloads full. Over the course of the academic year, mental health services were provided to 12 clients, most of whom attended eight or more sessions, responded positively to the treatment offered, and showed reductions in psychological distress. When the clinic ended, many clients wished to continue, and worked with their student clinician to find suitable referrals. Overall, we believe the Clinic achieved this first goal at a moderate level. Most indicators pointed to successful courses of treatment for the clients who received services; however, barriers to recruitment prohibited the clinic from maximizing its potential for providing these services to a larger number of clients.

The second goal was to provide training for students that integrated research and practice to develop their ability to understand and treat the mental health problems common to these populations. A core element of this training was reading and discussing primary literature. The team developed a robust syllabus that integrated readings on clinical diagnosis and etiology of NDs, physical and psychological effects of caregiving, psychotherapy treatment adaptation and evaluation for the populations of interest, cultural considerations in therapy, psychoeducation, psychopathology in late life, complicated grief, translating clinical experiences into published work, and more. The faculty and students shared responsibilities for leading discussions during the weekly seminar, which created a platform for students to connect their experiential learning from their cases with the empirical literature. Guest speakers made invaluable contributions via research presentations and case consultations. Close supervision by clinical supervisors was also critical for integrating and applying knowledge gained into psychotherapy treatment. Although having a larger number of cases would have provided additional opportunities for trainees to improve, apply, and consolidate their expertise, the trainees exited this clinic feeling well-prepared to treat other clients in the caregiver and PWND populations using empirically-supported treatments. This self-evaluation was corroborated by the supervisor evaluations of student progress with all

students meeting or exceeding training standards set by the larger Clinical Science program. We concluded the second goal was largely met.

The third goal was to create a cohort of student clinicians who could help train and supervise other UC Berkeley clinical science students to work with these populations in the future, and who would be prepared to create similar Specialty Clinics at other institutions after graduation. The Specialty Clinic clearly succeeded in the first steps toward this goal. The four participating students completed a thorough literature review related to PWNDs, CGs, and evidence-based treatments for these groups, gained experience working with these populations using evidence-based treatments, and received training in case formulation and individualized treatment planning. All of the students in the Specialty Clinic indicated that they would like to continue providing treatment to CGs and PWNDs as part of their future clinical work in the Psychology Clinic and beyond. Thus, by all measures, we concluded that this goal was fully met.

To continue this work in the future, students from this Specialty Clinic: (a) will hold a workshop to educate incoming students about these disorders and available treatments for working with these PWND and CG populations; (b) will serve as peer supervisors for students interested in providing therapy services to this population in the future; (c) will consult with other clinical science programs interested in creating similar Specialty Clinics; (d) created a repository of progress monitoring and outcome measures, intervention modules, and academic readings that are available for sharing with others; and (e) spearheaded the writing of this article based on their experiences with the Specialty Clinic.

Recommendations

For others interested in establishing Specialty Clinics in this area, we offer several recommendations. Our first recommendation, aimed at obtaining program buy-in, is to assemble a team of interested faculty, staff, and students in the semester prior (4–6 months) to the start of the Specialty Clinic. Team members should commit a minimum of two full semesters to the clinic, given the substantial start-up efforts required. This team should include at least one faculty member with academic and clinical expertise working with these populations. Supervisors should be identified who have expertise in evidence-based psychotherapy with adults. While not a requirement, we found it extremely valuable to include supervisors with a wide range of clinical orientations to increase opportunities for innovation in case formulations and intervention approaches. It is also helpful to include students who have prior clinical or research experience with older adults and/or NDs. Given the complexity of these diseases, we recommend that, if possible, clinics work with an interdisciplinary team of psychiatrists and neurologists to inform client care. We recognize that this may be challenging, especially for programs like ours that exist at universities without a medical school on campus.

The second recommendation, aimed at producing a balanced and organized training curriculum, is to develop a comprehensive bibliography of resources for the weekly seminar. The list of topics should include: disease etiology, diagnostic characteristics and processes, CG mental health issues, evidence-based treatments for PWNDs and CGs, and methods to

evaluate interventions (See online supplemental material). We highly recommend inviting local and, if possible, national experts with relevant research and clinical expertise to meet with the seminar. We also recommend adapting the training curriculum to meet case needs. The NDs in our clinic had primary neurocognitive deficits, which is reflected in our training materials. However, if ND cases had presented with primary motor or socioemotional symptoms, we would recommend identifying and incorporating curriculum relevant to those particular NDs.

The third recommendation, aimed at having a robust evaluation component, is to design an assessment including pre-treatment, post-treatment, and follow-up measures as well as briefer measures that allow session-by-session progress monitoring. Key constructs to measure with these populations include depression, anxiety, stress/burden, anger, loneliness/social connection and support, and guilt. Given that our Specialty Clinic operated within our existing Psychology Clinic, we had to utilize a number of clinic measures that are used with all Psychology Clinic clients. This limited the number of additional measures we felt we could use without over-burdening PWNDs and caregivers. However, the Geriatric Depression Scale (Yesavage et al., 1988) and Geriatric Anxiety Scale (Segal et al., 2010) would have helped assess outcomes particularly relevant to PWNDs and CGs. We recommend including these and other more specialized measures as ways of strengthening progress monitoring and assessing client outcomes. Additionally, we note that Specialty Clinics should consider adding a control group if possible (e.g., a waiting list control for oversubscribed clinics). Data from such groups can be critical for refining understanding of data on treatment efficacy (e.g., whether no change in a treatment group is actually a positive outcome). Work on this recommendation will need to commence early so that a solid evaluation plan is in place prior to starting to see clients.

The fourth recommendation, aimed at maximizing recruitment potential and client matriculation, is to utilize a multi-faceted community outreach effort, starting 2–3 months before the Specialty Clinic opens. A critical component of these outreach efforts should be to identify local organizations already in contact with PWNDs and CGs, including Veterans Affairs (VA) Medical Centers, hospitals, and clinics focused on neurology, memory care, movement disorders, psychiatry, geriatric psychiatry, and geriatrics. Active ongoing recruitment may encourage CGs to consider their own mental health and to engage PWNDs in mental health services. Although our Specialty Clinic did not end up working with any PWND/CG dyads, this may be clinically indicated in some instances and should therefore be highlighted in recruitment efforts.

The fifth recommendation, aimed at addressing particular vulnerabilities faced by this population, is to begin considering and designing accommodations for logistical challenges and unintended obstacles prior to opening the Specialty Clinic. Offering a range of service-delivery formats, including in-person and telehealth services, is beneficial for clients with accessibility issues and also for CGs who will experience increasing difficulties finding time away from the PWND for self-care. It is important to facilitate contact with clinicians or clinic staff to avoid lags in communication, such as can occur during recruitment, scheduling, and responding to questions. Frustrations encountered with administrative systems can rupture fledgling connections with new and existing clients resulting in early

attrition. Additionally, greater flexibility, information sharing, and coordination may be required when providing services to multiple family members by, for example, including family members in sessions with PWNDs to facilitate treatment planning and homework completion. Rather than creating strict firewalls between clients, coordinated care across service providers that adheres to ethical principles may be critical. Transportation needs should be discussed and financial burden from medical and care services should be considered when setting fees.

Conclusion

Our Specialty Clinic, which focused on PWNDs and their CGs, represents a small yet important step toward addressing a major gap in mental health care for a rapidly-growing group worldwide. We believe this kind of Specialty Clinic could be broadly beneficial to others. It offers students a unique opportunity to treat vulnerable, at-risk populations, which are often not seen in clinical science training programs. Working with a specialized population challenges students to expand their understanding of transdiagnostic mechanisms, case formulation techniques, evaluation methods, and evidence-based therapies. Such rich training increases students' readiness for clinical internships, especially for those sites that work with older populations and those with NDs, such as VAs. Moreover, students can obtain specialized training working with PWNDs and their CGs, which may open future career opportunities. Comprehensive and integrated care for PWNDs and CGs has not traditionally included clinical psychologists providing evidenced-based psychological treatment. However, as the mental health issues of CGs and PWNDs continue to emerge as major public health concerns, we foresee clinical psychologists (especially those who receive this Specialty Clinic training) as playing an increasingly important role in assessment, prevention, treatment, and research with these populations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Biographies

Esther S. Howe is a PhD student in the Clinical Science Program at the University of California, Berkeley. Esther's research aims to understand the impact of sexual assault on mental health. She is particularly interested in understanding how social reactions to sexual assault survivors contribute to PTSD development, and in incorporating passive measurement of physiology and social context into her work. Esther studies these topics using within-person symptom dynamics during the acute post-trauma period, and identifies group-level patterns of these dynamics. She sees her current research as an important first step towards the development of empirically-based momentary interventions that prevent PTSD.

Suzanne M. Shdo is a PhD student in the Clinical Science Program at the University of California, Berkeley. She majored in Biology at Chapman University, and received her Master of Public Health with an emphasis in Epidemiology and Mental Health from Boston University. Her research interests include the relationship between attention and emotional processing in individuals with neurodegenerative diseases. She is also interested in psychiatric symptoms experienced by patients with neurodegenerative diseases.

Matthew V. Elliott is a PhD student in the Clinical Science Program at the University of California, Berkeley. His research and clinical interests are centered on human emotion and self-control, which intersect in his work on emotion-related impulsivity. Matt is using experimental, neuroimaging, and meta-analytic techniques to study the neurocognitive systems that contribute to losses of control during periods of strong emotion.

Alice Y. Hua is a PhD candidate in clinical science at UC Berkeley and is completing her clinical psychology internship at UCSF during the 2020–2021 cycle. After internship, she will be a postdoctoral fellow at the UCSF Memory and Aging Center. Her research has focused on emotional functioning (e.g., emotional reactivity and empathy) as a window to understand early changes in neurodegenerative disease and to identify familial caregivers at risk for poor mental health.

Nadine M. Tang is a clinical social worker in private practice, an adjunct associate professor in the Department of Psychology at the University of California at Berkeley and an adjunct professor at Tsinghua University in Beijing. Her interests are in cultural differences as well as working in psychotherapy when patient and therapist come from different backgrounds.

Nina F. Dronkers is an Adjunct Professor at the University of California, Berkeley in the Department of Psychology and an Adjunct Professor at the University of California, Davis in the Department of Neurology. She is a retired Research Career Scientist and Director of the Center for Aphasia and Related Disorders with the Department of Veterans Affairs. Dr. Dronkers' research and clinical interests have always focused on understanding the speech, language, and cognitive disorders that occur after injury to the brain, and utilizing neuroimaging techniques that can assist in diagnosis and recovery.

Robert W. Levenson is a professor in the clinical science area in the Department of Psychology at the University of California, Berkeley. He also serves as president of the Board of the Directors of the Psychological Clinical Science Accreditation System (PCSAS). His research is in the area of human emotion, with particular focus on how emotions change during healthy aging and in the context of dementia and other neurodegenerative diseases.

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Public Significance Statement

Neuropsychiatric and psychiatric problems for persons with neurological disorder and their caregivers have become a significant public health problem, in part because of the dramatically aging population. However, training for psychologists to help prepare them for working with adults with neurological disorders and their caregivers is lacking. In this article, we describe the development and implementation of a Specialty Clinic for clinical science trainees in a university setting focused on these underserved populations.

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TABLE 1:

Descriptions of Clients

Group	Mean Age (range)	Gender (M/F)	Race	PWND: Type	# of sessions (range)	Relationship to PWND
Caregiver (n=7)	57 (44–79)	0/7	White - 6 Asian - 1	Dementia - 5 Stroke - 2	12 (1–29)	Daughter - 3 Wife - 3 Friend - 1
PWND (n=3)	63 (40–78)	2/1	White - 2 Asian - 1	TBI - 2 Neuromuscular Spasticity - 1	13 (16–22)	Self - 3

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TABLE 2A.

Group Depression Scores, measured using the DASS-21

<i>Group (Depression)</i>	<i>Session 1 Mean (SD)</i>	<i>Final Mean (SD)</i>	<i>Change Score</i>
Caregivers (n=7)	13.4 (11.2)	13.3 (14.2)	-0.1
PWNDs (n=3)	18 (10)	23 (9.9)	+5

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TABLE 2B.

Group Anxiety Scores, measured using the DASS-21

<i>Group (Anxiety)</i>	<i>Session 1 Mean (SD)</i>	<i>Final Mean (SD)</i>	<i>Change Score</i>
Caregivers (n=7)	10 (10.6)	5.7 (5.7)	-4.3
PWNDs (n=3)	20 (2.0)	8 (2.8)	-12

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TABLE 2C.

Group Stress Scores, measured using the DASS-21

<i>Group (Stress)</i>	<i>Session 1 Mean (SD)</i>	<i>Final Mean (SD)</i>	<i>Change Score</i>
Caregivers (n=7)	16 (9.5)	12.4 (13)	-3.6
PWNDs (n=3)	20 (14)	19 (7.1)	-1

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