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Diagnostic Labels, Stigma, and Participation in Research Related to Dementia and Mild Cognitive Impairment

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Abstract

Health care professionals use diagnostic labels to classify individuals for both treatment and research purposes. Despite their clear benefits, diagnostic labels also serve as cues that activate stigma and stereotypes. Stigma associated with the diagnostic labels of dementia and mild cognitive impairment (MCI) can have a significant and negative impact on interpersonal relationships, interactions with the health care community, attitudes about service utilization, and participation in clinical research. The impact of stigma also extends to the family caregivers of individuals bearing such labels. In this article, we use examples from our investigations of individuals with dementia or MCI and their family caregivers to examine the impact of labeling and stigma on clinical research participation. We also discuss how stigma can affect numerous aspects of the nursing research process. Strategies are presented for addressing stigma-related barriers to participation in clinical research on dementia and MCI.

Across the life span, stigma associated with diagnostic labels can interfere with adequate provision of care, patients' willingness to seek care, family members' experience of living with the patient, and both patients' and families' willingness to participate in research associated with the disease or disorder. In this article, we explore the impact of labeling and stigma on clinical research participation among older adults with or at risk for dementia and their family caregivers. As a foundation, we provide background information on dementia and mild cognitive impairment (MCI). We then examine the nature of stigma associated with diagnostic labels of neuropsychiatric illness in general (encompassing functional psychiatric illnesses such as mood disorders, as well as conditions with organic etiologies) and describe evidence regarding the stigma experienced by individuals who have been diagnosed with dementia. Using examples from our own research, we explore how stigma can affect the nursing research process with older adults who have a diagnostic label of either dementia or MCI and their

family caregivers. We also suggest strategies to diminish the negative impact of stigma on clinical research with these patients and their family caregivers.

Background

Gerontological nurse investigators must be cognizant of the stigma associated with diagnostic labels related to dementia or milder forms of cognitive impairment, as these conditions are highly prevalent among older adults. Current estimates suggest that 5.2 million people in the United States have Alzheimer's disease or another form of dementia, and projections indicate as many as 16 million older Americans will be affected by dementia by mid-century (Alzheimer's Association, 2008b). The numbers also reflect a growing demand for effective educational and support programs for family caregivers as they provide care and assistance to the impending wave of people with dementia (Institute of Medicine, 2008; National Institute of Nursing Research, 2006). Therefore, to provide essential research and develop effective treatment programs, investigators should be prepared to address and attempt to overcome issues related to labeling and stigma among the patient and family populations affected by dementia or MCI.

Dementia and MCI

Both dementia and MCI are important targets for prevention and intervention research. Dementia is a common syndrome among older adults and is associated with a number of underlying disease pathologies (e.g., Alzheimer's disease, vascular dementia, Lewy body dementia). The pathological processes associated with Alzheimer's disease and other kinds of dementia are progressive, resulting in continued deterioration of cognitive, behavioral, and social functioning over time. To receive a diagnosis of dementia, an individual must demonstrate cognitive deficits that involve both memory impairments and a disturbance in at least one other area of cognition (e.g., aphasia, apraxia, agnosia) and a disturbance in functioning (American Psychiatric Association [APA], 2000). Such functional deterioration results in substantial personal suffering and economic strain for affected individuals and their family members.

The insidious progression of symptom onset in dementia often includes a subsyndromal phase during which an individual expresses symptoms of, but does not meet diagnostic criteria for, dementia (Petersen, 2001). Referred to as MCI, this subsyndromal period is associated with memory deficits or other mild cognitive dysfunction with little or no effect on everyday functioning (Winblad et al., 2004). Research indicates that, depending on the sampling strategy and operational definition of MCI used, annual conversion rates to dementia vary from 10% to 15% per year, compared with 1% to 7% per year for individuals who do not have MCI (Petersen et al., 1999). Because MCI is a far-from-perfect predictor of dementia (Bruscoli & Lovestone, 2004), it is generally given as a "research" diagnosis rather than for purposes of clinical care. A diagnostic label of MCI allows clinical researchers to identify individuals eligible for clinical trials testing the effectiveness of strategies to prevent or delay the onset of dementia.

Diagnostic Labels

Using current nosologies, health care professionals assign diagnostic labels to classify individuals for both treatment and research purposes. Diagnostic labels allow clinicians and researchers to assume that all members of a group are generally homogeneous in the underlying nature of the illness, regardless of whether there is some variability in the presentation of symptoms or circumstances surrounding illness onset. In other words, diagnostic labels distinguish patient groups by a set of definable boundaries (APA, 2000). Thus, diagnostic labels serve several goals. First, they provide an efficient way for clinicians and researchers to

understand a large amount of information (Frances, First, Pincus, Widiger, & Davis, 1990; Rosch & Mueller, 1978). They also provide a convenient means for describing patients that includes the presentation of symptoms and may imply the expected course and prognosis. Lastly, diagnostic labels may suggest etiology as well as point the way toward specific interventions that may prevent or ameliorate the consequences of the condition (Corrigan, 2007).

Despite the benefits of diagnostic labels, such labels often serve as cues to signal stereotypes. The negative consequences of labeling appear to arise through two social psychological processes. First, when an individual is diagnosed with a neuropsychiatric disorder, cultural ideas associated with those with mental illness (e.g., incompetent, dangerous) become personally relevant and foster negative feelings of self. Second, these personally relevant cultural meanings transform into expectations that others will reject them, and these expectations can trigger defensive behaviors aimed at preventing that rejection (Link, 1987; Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). One such behavior may be reluctance to learn about or participate in research studies in an effort to avoid the stigma associated with the diagnostic labels. Below, we review the concept of stigma and discuss how behavioral manifestations of stigma impact the lives of individuals diagnosed with dementia.

Stigma

In Goffman's (1963) seminal work, he used the term *stigma* to refer to “an attribute that is deeply discrediting within a social interaction” (p. 3). Individuals possessing such an attribute are different from others in ways that are undesired and shameful. The stigmatized individual is “reduced...from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p. 3). Stigmas are typically the attributes that, when observed by a majority group member, may lead to labeling, stereotyping, separation, status loss, and discrimination (Link & Phelan, 2001). Labeling and stereotyping involve the recognition of differences and the assignment of social salience to those differences. In the context of illness, labeling is the recognition that a person with a particular diagnosis differs from the norm in ways that have social significance. Stereotyping is the assignment of negative attributions to these socially salient differences (i.e., the perception that the differences are undesirable). Separation occurs when the reactions of others to these differences lead to a pronounced sense of “otherness” or “felt stigma” (Green, Davis, Karshmer, Marsh, & Straight, 2005) (i.e., the individual's personal awareness that others are treating him or her differently due to some personal attribute).

Status loss and discrimination occur when stigma interferes with an individual's ability to participate fully in the social and economic life of his or her community. In these circumstances of “enacted stigma” (Green et al., 2005), there is most likely a power differential favoring those without the trait over those who have it. Thus, the stigmatization of individuals with a specific illness or condition is a complex process involving the labeling of individual differences, the negative evaluation of those differences by others, others' adverse reactions, and negative social and emotional outcomes for the affected individual (Green et al., 2005).

In addition to public stigma, people with certain diagnostic labels may also experience self-stigma, or an internalization of the stereotypes held by the general public (Corrigan, 2007). This internalized or self-stigma may deter individuals from seeking treatment and social services, even when the opportunities are available, simply to avoid the stigma associated with that label. Research in this area suggests that individuals may choose not to seek professional help as a means of protecting themselves from embarrassment and feelings of inferiority or incompetence (Nadler, 1990; Wills & DePaulo, 1991). Further, stigma tends “to spread from the stigmatized individual to his/her close connections” (Goffman, 1963, p. 30). Research in

this area suggests that both primary caregivers and other family members experience stigma and often experience increased emotional distress and social isolation (MacRae, 1999).

Research Related to Stigma and The Dementia Label

The stigma and discrimination attached to a diagnostic label of dementia are strongly associated with suffering, disability, and economic losses (Graham et al., 2003). Several elements of this stigmatization are described in the literature. Dementia is often mistaken as a natural part of aging (Graham et al., 2003; Lebowitz & Niederehe, 1992). When dementia is considered an undesirable natural process, rather than a pathological condition, part of the stigma associated with it may include the notion that the condition is untreatable. To the extent that patients, their families, and the general public incorrectly believe that treatment is not useful, societal mandates to finance care or reimburse care costs will reduce consumers' access to resources and opportunities for treatment and related social services. In certain instances, the dementia diagnosis is used to exclude individuals from some forms of health care, such as inpatient treatment or nursing home care (except on dementia-specific units) (Graham et al., 2003). A consequent inability or failure to obtain treatment reinforces destructive patterns of low self-esteem, isolation, and hopelessness (Graham et al., 2003).

Specific symptoms seen in some individuals with dementia (e.g., disturbed thinking and behavior, poor self-care, incontinence) are powerfully stigmatizing in the community and in health care settings. Individuals with dementia are often perceived as having little to no quality of life or capacity for pleasure. Therefore, personal preferences and cultural or religious beliefs may be ignored (Graham et al., 2003). Evidence suggests that stigma leads people to avoid socializing with, employing, working with, renting to, or living near individuals with dementia (Graham et al., 2003). A survey of 1,000 participants exemplifies this point: 81% of respondents believed they would be looked upon or treated differently if others knew they were diagnosed with dementia (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000).

Research shows that stigma and discrimination extend to family caregivers of individuals with dementia (Benbow & Reynolds, 2000; Jolley & Benbow, 2000). For example, their loved one's symptoms (e.g., poor self-care, incontinence) are often regarded as evidence of neglect (Graham et al., 2003). Furthermore, to the extent that individuals attempt to avoid social interactions with patients with dementia, those patients' family caregivers may be inadvertently excluded as well. Thus, for example, when one member of a married couple is stigmatized, the spouse is likely to suffer the consequences as well.

Individuals with dementia have themselves described their experiences with stigma and other social changes brought about by the diagnostic label of dementia. For example, a study exploring responses of support group members with early-stage dementia found the most commonly voiced themes were concerns about the nature of the disease and the diagnostic process, awareness of the stigma attached to a diagnosis of dementia, and effects of the diagnosis and the disease on relationships with families and friends (Yale, 1995). These issues were of particular concern because participants wanted to keep their lives full and meaningful for as long as possible, as well as prepare appropriately for the future (Yale, 1995).

The Alzheimer's Association (2008b) analyzed dialogues of more than 300 people living with early-stage Alzheimer's disease at nationwide town hall meetings and virtual town meetings held online at the Alzheimer's Association Web site. In this study, participants shared their experiences and perspectives on how they wish to be viewed, respected, engaged, and treated by health professionals, researchers, and the general public. Common themes identified by participants included stigma associated with a diagnostic label of Alzheimer's disease and its impact on relationships, dissatisfying interactions with the health care community, uncertainty about availability of support services, sources of major concern in daily life, and a desire to

stay involved and make a difference. An overriding theme that emerged in the town hall meetings was that people with early-stage Alzheimer's disease are misunderstood because of myths and misconceptions about the disease and that misunderstanding leads to a dominant negative stigma associated with having the condition (Alzheimer's Association, 2008a).

Research Related to Stigma and The MCI Label

Considerably less is known about patients' and family members' perceptions of any stigma associated with the label of MCI. The literature confirms confusion related to the MCI diagnosis (Alzheimer's Association, 2008a; Frank et al., 2006; Whitehouse & Moody, 2006). In an effort to better understand the experience of living with MCI, Lingler et al. (2006) used qualitative methods to examine how individuals "make sense" of the fact that they had received a research diagnosis of MCI. Findings indicated that assigning meaning to the diagnosis was a fundamental aspect of living with the diagnosis among study participants. According to Goffman (1963), assigning meaning to a diagnostic label entails the recognition that the person with the label differs in some way from the general public. In the Lingler et al. (2006) study, the meaning participants assigned to their diagnoses varied widely depending on their expectations related to normal aging, personal experience with dementia, and concurrent health problems. For example, an individual who viewed memory loss as an expected part of the aging process was relatively unaffected by the MCI label, stating, "It's just a matter of putting a name on the condition I was aware of" (Lingler et al., 2006, p. 796). By contrast, those who viewed MCI as a definite precursor to Alzheimer's disease voiced significant distress.

Frank et al. (2006) also examined responses to receiving a research diagnosis of MCI or early dementia among a sample of patients and their family caregivers. Emerging themes included uncertainty of the diagnosis, skill loss, changes in social and family roles, embarrassment and shame, emotionality, insight into their condition, and burden. Affected individuals reported frustration with recognized memory problems, diminished self-confidence, fear of embarrassment, concerns about changing family roles due to progressively worsening cognitive impairment, and anxiety.

While research suggests that diagnostic labels pertaining to dementia and cognitive impairment are associated with stigma, it also indicates that a label of dementia or MCI could evoke sympathy and helping behaviors in some circumstances. This has been observed for other conditions (Ray, Raciti, & MacLean, 1992) and may result from differential attributions of responsibility (Kroska & Harkness, 2006). For example, Weiner, Perry, and Magnusson (1988) compared study participants' perceptions of individuals with conditions for which their own behavior was believed to be a contributory factor (i.e., AIDS and obesity) with those of individuals believed to have little or no role in the onset of their condition (i.e., Parkinson's disease and multiple sclerosis). Participants reported considerably greater pity, less anger, and more help-giving emotional responses to the latter patient group (Weiner et al., 1988). In short, stigma and perceptions of blame may be eradicated in the presence of certain medical diagnoses, making it less likely the patient will be criticized or rejected for deviant behavior and more likely he or she will receive help (Ray et al., 1992). The provision of appropriate disease labels, particularly when the labels insinuate a disease process, may lead to clear benefits for patients, such as seeking and receiving appropriate treatment and support services. Thus, as public awareness increases regarding the organic etiology of dementia and milder degrees of cognitive impairment—or if public knowledge increases regarding the benefits of treatment for dementia—we might expect that stigma associated with these conditions would be lessened.

There is already some evidence that individuals with cognitive impairment can be viewed with compassion by the general public. For example, in a study from Israel, Werner and Davidson

(2004) asked participants to read vignettes describing individuals with dementia. The investigators found that the vignettes elicited more positive (compassion and concern) than negative (rejection, disgust, anger, irritation, and dismay) reactions, particularly among women. In a study by Wadley and Haley (2001), participants responded to vignettes describing “your mother” or “your father” exhibiting behaviors consistent with a diagnosis of dementia, major depression, or no label at all (e.g., irritability, forgetfulness, social withdrawal). Results showed that the diagnostic label of Alzheimer's disease—and to a lesser extent the major depression label—produced more sympathy toward the parent, less blame, and greater willingness to help. Although responding to vignettes may differ from responses in actual encounters with those with dementia, these studies suggest that the provision of diagnostic labels may, under some circumstances, facilitate compassionate attitudes and enhanced caregiving toward older adults.

Stigma and Participation in Clinical Research

Investigators have identified a number of barriers to research participation among individuals with dementia and their family caregivers. Such barriers include the perception of limited to no benefit, concerns about the procedures and tests involved, lack of time and resources, and difficulty accepting the diagnosis (Connell, Shaw, Holmes, & Foster, 2001). The stigma associated with diagnostic labels of dementia or MCI may also influence many aspects of the research process, from identification and recruitment to participant retention. It can affect research involving patients themselves, as well as studies of their immediate family members (Table). While stigma may be interconnected with the barrier related to accepting the diagnosis, stigma associated with labels of dementia and MCI goes well beyond this difficulty. In the following sections, we use examples from our investigations of individuals with dementia and MCI and their family caregivers to discuss how stigma can affect the research process.

Stigma and Identification of Dementia Research Participants

Initially, the stigma associated with the label of dementia or MCI may prevent some individuals from seeking an evaluation of their cognitive symptoms. This is a concern for two reasons. First, some conditions can mimic early dementia and are treatable (e.g., vitamin B₁₂ deficiency, sleep apnea). When individuals refuse to undergo a diagnostic evaluation for dementia, they are also refusing to avail themselves (or their family caregivers) of potentially beneficial treatments. Second, lack of willingness to be evaluated for a diagnostic label of dementia also means that investigators conducting research to ultimately improve the lives of affected individuals have a smaller and less generalizable pool of potential participants for clinical trials.

In our investigations of individuals with dementia and MCI and their family caregivers, samples are drawn from the research registry of an Alzheimer's Disease Research Center (ADRC). Individuals coming to the memory disorders clinic of the ADRC with complaints of memory or other cognitive impairments undergo a standardized clinical research evaluation, which consists of a medical and neurological history and examination, psychosocial assessment, psychiatric interview, neuropsychological testing, and brain imaging. This multidisciplinary evaluation is necessary to rule out treatable forms of cognitive impairment and determine a possible or probable etiology for dementia syndrome (if present).

However, how representative are samples when they are derived from an ADRC? It is unlikely that individuals who are either fearful of a diagnosis of cognitive impairment or the stigma associated with the diagnosis would willingly undergo such an evaluation. Indeed, in our samples of individuals with dementia and MCI and their caregivers drawn from the ADRC, we have found that the vast majority (92%) were European American, and a high proportion (78%) had more than a high school education (Garand, Dew, Eazor, DeKosky, & Reynolds, 2005). Studies show that stigma associated with diagnostic labels may be perceived as more

severe among some ethnic groups (Bowes & Wilkinson, 2003; La Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007). Further, stigma may be stronger among individuals with less education about a given condition (Corrigan & Watson, 2007). Therefore, it is not surprising that our samples have been relatively homogeneous in ethnicity and educational level.

Recommendations for Improving Participation in Dementia Research

Public awareness programs aimed at changing individuals' openness to discussions of cognitive symptoms and dementia may increase general willingness to seek evaluation and care. Studies show that relatively brief educational programs lead to significantly improved attitudes about mental illness (Corrigan & Penn, 1999), and the same may be true for educational programs targeted at dementia. Further, it is important that health care providers offer both written and verbal information (in nonmedical terms) about cognitive symptoms, the potential for neurodegenerative disease in late life, and treatments available for these kinds of disorders. This is supported by a study of family dementia caregivers in which nearly half of the respondents believed they were not given enough information about dementia, suggesting that clinicians need to do a better job of educating families about dementia and directing them toward appropriate resources (Holroyd, Turnbull, & Wolf, 2002)

Stigma and education about Potential Research Studies

Fear of public stigma and/or an individuals' own stereotypes about dementia (self-stigma) are likely to reduce patients' or family members' willingness to learn about available research studies. To the extent that they are unwilling to accept that they (or their loved one) have or are at high risk for a disease, and risk the reactions of others, they may be unwilling to even contemplate participation in a study focused on behavioral issues related to the disease. In one of our ongoing studies, we have found that nearly one quarter of potential participants indicated they were not interested in learning about MCI caregiving or behavioral intervention studies. This may be interpreted as an attempt to avoid a pronounced sense of "otherness" and "felt stigma" (Green et al., 2005).

Recommendations for Improving education about Potential Dementia and MCI Studies

When individuals are reluctant to consider participating in studies due in part to stigma, investigators need to pay particular attention to the language used during recruitment encounters. For example, rather than continued use of the term "MCI," we often use the phrase "changes in thinking" when referring to the condition. We are not suggesting that researchers or clinicians avoid providing information about the diagnosis of MCI. Rather, we have found that once a diagnosis is disclosed, there is a need to consider using value-neutral and label-free language that is less likely to connote abnormality or foster a sense of "otherness."

As researchers, we also need to give attention to the language used and images portrayed in informational brochures describing our studies. For example, when investigators are interested in studying a racially diverse group of individuals with cognitive impairment, it is important to use language that is appropriate for the general public (a 6th grade reading level is often recommended), use typesettings appropriate for older adults (at least a size 14 font to compensate for sensory changes in late life), and incorporate images of individuals from different racial backgrounds. If targeting a specific minority population for study participation, culturally tailored study materials may be especially useful. In any case, allowing potential participants to review recruitment materials at their own pace and in the privacy of their own homes may diminish a sense of public stigma.

Participation in Dementia Research

Another defensive behavior associated with stigma is reluctance to participate in research studies designed to test the effects of treatment strategies to improve the lives of individuals with a stigmatizing label. We suspected this to be the case when trying to recruit potential family caregivers into a prevention trial designed to enhance their coping resources in living with a loved one with MCI. Many caregivers of individuals with MCI were not ready to accept the fact that an MCI diagnosis was associated with an increased risk that their loved one would progress to dementia and that they themselves would become a dementia family caregiver.

Our ongoing study recruitment rates have been much lower (nearly one half) for family members of individuals diagnosed with MCI, when compared with recruitment rates for family members of individuals with early-stage dementia. Common reasons given for study refusal by the dementia family caregivers include being “too busy” and not interested in a caregiver study. MCI family caregivers gave reasons for refusing to participate that were markedly different from those given by dementia family caregivers, including that their loved one was “not sick enough” and that it was “too upsetting to think about” the new diagnosis. It is possible these recruitment rates are related to the fact that dementia family caregivers have been providing care and assistance to their loved ones long enough to understand they need information and skill training related to their changing roles and responsibilities.

Recommendations for Improving Participation Rates in Dementia and MCI Studies

Study participation rates suggest that individuals with MCI and their family caregivers need time and information as they come to terms with the MCI research diagnosis. Providing psychological support (e.g., active listening, venting of feelings) while giving participants factual information about MCI is very important. It is also helpful to educate potential participants about the societal benefits of study participation. Often, individuals will participate in clinical trials for altruistic reasons. If they understand that they may or may not directly benefit from the treatment protocol they are assigned to—but that their involvement may help investigators answer important questions about effective treatment strategies—a number of individuals will enroll in clinical studies to benefit society and advance scientific knowledge.

Another strategy designed to recruit participants into dementia or MCI clinical trials is the training of “peer recruiters.” Potential participants may be more agreeable to learning about dementia or MCI studies from someone who looks like them and speaks in a similar manner. Further, investigators can ask current study participants to act as “champions” for the project by telling friends and family members about the benefits they received from study participation and giving study informational brochures to relevant groups.

Retention of Research Participants

Once participants have enrolled in a research study, procedures may require continued participation over an extended period of time. To the extent that there is considerable loss to follow up or differential loss to follow up in one treatment group versus another, study findings may be biased and not generalizable. In our current trial testing the effects of a self-management intervention with MCI family caregivers, several participants withdrew from the study after completing the baseline assessment questionnaires. Stigma may have played a role in their decision to withdraw from the study, as these participants stated that they were uncomfortable with the questions asked during the initial assessment session. When study participants verbalize discomfort with the assessment questions, it may indicate a need for psychological support as affected individuals and their family members come to terms with the diagnosis of MCI or dementia and the stigma associated with it.

Another reason for terminating study participation is the amount of time required for participation in longitudinal behavioral interventional trials. It is possible that participants who withdraw from a study because they are “too busy” do not find the intervention useful or helpful. While this is always a possibility when conducting experimental intervention studies, the research team can implement strategies to foster continued study involvement.

Recommendations for Improving Retention of Research Participants

In an effort to retain participants in our studies, we pay particular attention to the study location and language used when intervening with these individuals. In an attempt to avoid negative stereotypes associated with the ADRC or a memory disorders clinic, we conduct studies of individuals with MCI and their family caregivers in the person's home or another location of the participant's choosing (e.g., local library). A willingness to drive (up to 200 miles) to the participants' homes is a kind of “thank you” to our participants for their time and efforts, while helping them avoid the stigma associated with being seen at a memory disorders clinic. Further, partnering with the participant in the delivery of the intervention and data collection fosters the therapeutic relationships and treatment fidelity needed to conduct longitudinal evaluation of psychoeducational interventions.

As discussed above, we also pay close attention to the language used to recruit and intervene with this population. We remove any reference to the ADRC or memory disorders clinic from our written (mailed) communications. In addition, we use simple (nonmedical) terminology to describe MCI, dementia, and the fact that MCI is a risk factor for the future development of dementia. Once that information has been successfully conveyed, we attempt to use the terminology preferred by the family caregiver (e.g., “mild memory problems” or “changes in thinking”) when conducting the remainder of the intervention sessions in hopes that our communication style does not contribute to negative stereotypes and respondent burden.

Research treatment Protocol Fidelity

Stigma may also affect treatment fidelity because participants frequently interrupt the treatment protocol to talk about the effects of MCI on their lives. In the study described above, the research interventionists are frequently required to put the treatment protocol “on hold” while they allow participants to vent their frustrations related to their current caregiving responsibilities, fears of stigma, and what the future holds for them and their loved one with cognitive impairment. Having to put a protocol “on hold” indicates a clear need for qualitative studies to understand the lived experience of individuals adjusting to a stigmatizing diagnosis (e.g., Lingler et al., 2006).

When it is necessary to put a protocol temporarily “on hold,” we believe it is important to foster a therapeutic relationship by and allowing participants to verbalize negative feelings associated with their loved one's diagnosis. Yet, it is important that the interventionists skillfully (and relatively quickly) direct the participant's attention back to the treatment at hand. This is very important because if the two treatment arms of a clinical trial differ in the amount of time and attention given to participants, it will not be possible to determine whether any differences in outcomes between the two arms are due to differences in content (e.g., new intervention versus a standard care condition) or simply due to differences in time spent with the interventionist.

Recommendations for Improving treatment Protocol Fidelity

Investigators also must consider respondent burden when attempting to retain participants in longitudinal studies. If the treatment protocol or follow-up questionnaires are burdensome for study participants to complete, they will not participate fully in the research process (i.e., not completing homework assignments, failing to respond to every item on a questionnaire). We address these concerns by traveling to our participants' homes (or other convenient location of

their choice) and having a research associate administer the lengthy study questionnaires face to face. If participants appear tired or burdened by the questions asked, research associates are trained to terminate the session and make an appointment with the participant to complete the questionnaires over several sessions. A willingness to extend the data collection over two face-to-face sessions improves the quality of the data obtained while allowing participants an opportunity to ask questions about the MCI diagnosis and clarify any misconceptions they have about the condition. Weekly face-to-face and telephone contact with our participants helps them complete the necessary homework assignments.

Lack of Support from Others

Dementia and MCI family caregivers need the support and understanding of friends and family members as they learn about MCI, dementia, and the family caregiving role. Yet, the stigma associated with having a family member with a cognitive disorder can interfere with such support. In a study designed to learn what it is like to live with a spouse with MCI, several participants endorsed deteriorating relationships with family and friends since their spouse had been diagnosed with MCI (Garand et al., 2007). In an ongoing study by Lingler and colleagues of individuals and family members affected by MCI, one participant made urgent requests that the study coordinator not call her while her daughter was in town. She did not want her daughter to know that she was involved in a "memory study." Another participant complained about receiving mail with the phrase "Alzheimer's Disease Research Center" on the return address label and letterhead. He did not want others to see literature from the ADRC in his home. While these examples suggest a lack of support from family members, they can also be understood as defensive behavioral responses to a stigmatizing diagnostic label of dementia or MCI.

Recommendations to enhance Support from Others

Investigators must ascertain participant preferences for receiving telephone calls or written communications related to the study. If written materials are mailed to study participants, they should be free of stigmatizing language and negative stereotypes. While we believe it is important to be honest with participants when teaching them about MCI, we can lessen the impact of stigma by using the participant's preferred terms in discussions, as noted above. It is also important to ask where and when participants prefer to receive telephone calls from study personnel. Some participants ask that we call them at work or on specific days when they will be alone and can talk in private. A willingness to adjust our schedules to address participant preferences not only reduces participant burden but may ultimately lessen any felt stigma and enhance support from family and friends.

Conclusion

Dementia and MCI are diagnostic labels that have considerable use for health care providers and researchers in delineating specific patient populations that may benefit from clinical and research attention. However, these labels are associated with significant stigma that may affect individuals' willingness to seek and receive care, as well as participate in clinical research. Although a number of barriers that may be related to the stigma associated with dementia and MCI diagnostic labels arise at each stage of the research process, specific steps can be taken to reduce the impact of these barriers on the successful completion of research in this area. It is critical that researchers actively work to overcome these barriers to ensure the recruitment and retention of participants who are as representative as possible, and to treat those individuals with maximum respect throughout the research process.

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Table
Impact of stigma on clinical research related to cognitive Disorders

Issues in Clinical Research of Cognitive Disorders	Behaviors Potentially Resulting from Stigma	Strategies to Address Behaviors Associated with Stigma
Identification of research participants	Unwillingness to seek evaluation of stigmatizing symptoms	<ul style="list-style-type: none"> • Provide general education to the public to improve knowledge and attitudes related to dementia and mild cognitive impairment (MCI). • Avoid use of medical jargon.
Education about potential research studies	Reluctance to learn about ongoing clinical studies that may benefit individuals with a stigmatizing diagnostic label (e.g., dementia)	<ul style="list-style-type: none"> • Use nonthreatening (label-free and value-neutral) language and images in informational study brochures and advertisements.
Participation in research	Unwillingness to enroll in clinical studies designed to benefit individuals with a stigmatizing diagnostic label	<ul style="list-style-type: none"> • Provide information and psychological support as individuals and their family members come to terms with the diagnosis of MCI or dementia. • Reinforce study participation for altruistic reasons. • Use “peer recruiters” and “study champions.”
Retention of research participants	Unwillingness to continue with clinical studies after assignment to treatment groups	<ul style="list-style-type: none"> • Use nonstigmatizing language and images on printed materials for written and verbal interactions with research participants. • Conduct clinical studies in the participant's home or other convenient location. • Foster positive (therapeutic) relationships among study participants and the research team.
Treatment protocol fidelity	Unwillingness to follow treatment protocols when the intervention reminds the person he or she has a stigmatized condition	<ul style="list-style-type: none"> • Monitor for participant burden and modify the protocol accordingly (e.g., extend one session over two home visits when the participant appears tired). • Conduct clinical studies in the participant's home or other convenient location.
Lack of support from others	Relationships with family and friends are affected by the stigmatizing condition	<ul style="list-style-type: none"> • Honor participants' requests regarding disclosure of study participation and preferred times to be contacted by study personnel. • Use nonstigmatizing language and images on printed materials for written and verbal interactions with study participants and their family members.