


Patients' and Family Members' Subjective Experiences of a Diagnostic Evaluation of Mild Cognitive Impairment

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Abstract

Background: People with a diagnosis of mild cognitive impairment (MCI) often struggle with uncertainty and fear when learning of and coping with their diagnosis. However, little is known about their experiences and perspectives, and those of their care partners, when seeking out and undergoing a diagnostic evaluation for their cognitive symptoms. **Method:** This study is a secondary analysis of a focus group discussion that was initially conducted to learn the perspectives and experiences of participants and their care partners during a mock disclosure session of brain scan results. Participant's broader views on their experience of completing a cognitive evaluation resulting in an MCI diagnosis were evaluated in this study. Analysis used qualitative content methodology and line-by-line coding which generated categories and themes. **Results:** The (1) "presence of a threat" and (2) attempts to "minimize the threat" emerged as overarching themes driving the process of seeking out a diagnostic evaluation for cognitive symptoms. Subthemes that highlight the complexity of the presence of a threat included the "fear of stigma," and the "emotional reactions" related to an MCI diagnosis. Three additional subthemes represented approaches that participants and their care partners used to minimize threat of MCI: "use of language" to minimize the threat; "information sharing and withholding"; and the "use of social support to legitimize personal experiences." **Conclusion:** These findings add to the literature by elucidating the uncertainty, fears, and coping strategies that accompany a diagnostic evaluation of MCI.

Keywords

mild cognitive impairment, Alzheimer disease, medical decision-making, patient perspectives/narratives, qualitative methods

Background

There is broad consensus among clinicians and researchers that cognitive functioning in late life can be classified along a wide range of performance levels including normal age-related changes, mild cognitive impairment (MCI) and various dementia syndromes, such as Alzheimer disease (1). Clinicians who evaluate and diagnose those complaining of cognitive decline face the task of explaining to patients and families the distinctions among these diagnostic entities and their relationships to one another. As an intermediate state between normal cognitive aging and dementia, MCI may be particularly difficult for lay individuals to understand as distinct from normal aging at the one end of the spectrum, and dementia at the other.

Recognizing the potential for varying interpretations of an MCI diagnosis, several researchers have sought to explore what having MCI means to affected patients. Using qualitative methodology, Beard and Nairy realized themes of

stigma and uncertainty surrounding an MCI diagnosis (2). They also posited that the medicalization and new diagnostic classifications of cognitive impairment contribute to this

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uncertainty and fear. In a meta-synthesis of qualitative studies, Gomersall et al developed conceptual themes to describe the experiences of living with an MCI diagnosis (3). They described 2 themes that were pervasive among qualitative studies of persons with MCI: (a) “living in the world” which provides a generalized account of the experiences of coping with an MCI diagnosis, while (b) “living with ambiguity” describes the sense of uncertainty entailed in living with an unknown future. Although a robust group of studies has documented the subjective experiences of those living with MCI, considerably less is known about the experience of seeking out and undergoing a diagnostic evaluation for cognitive symptoms. One study examined this process using discourse analysis as a method of investigating the deliberations of participants considering pursuing and MCI diagnosis (4). The authors observed 3 primary themes, “not knowing,” what MCI is, “knowing,” about the aging and dying process, and “not wanting to know” about dementia, indicating a range of perspectives on the diagnostic process (4). The current study presents additional perspectives from patients and care partners of those undergoing a diagnostic evaluation of MCI.

Methods

Sample

The current study recruited a subsample of participants from an initial study that was designed to evaluate patient and family member satisfaction with and comprehension of new patient education materials.

The Initial Study

In the initial study, persons with MCI and their care partners participated in mock amyloid imaging results disclosure sessions, during which they were provided with fictitious, but realistic, brain scan results and which was immediately followed by individual interviews with all participants. Ten MCI care dyads were recruited to the initial study from a university-affiliated Alzheimer Disease Research Center (ADRC) cohort of individuals with MCI and their care partners who had previously agreed to be contacted regarding research participation. All patients had completed an ADRC memory evaluation, including a medical and neurological evaluation, psychiatric interview, neuropsychological testing, brain imaging, and a psychosocial assessment. Purposive sampling was used to maximize the diversity of study participants particularly with regard to race and educational level. The sampling frame included all ADRC patients who (a) had a current ADRC consensus diagnosis of MCI (isolated impairment in memory, isolated deficit in nonmemory domain, or mild deficits in multiple cognitive domains; 5,6) and (b) had the capacity to provide written informed consent to participate. Those excluded from the study were ADRC patients who (a) are familial AD genetic mutation carriers and already received biomarker-derived information

regarding their dementia risk; or (b) have participated in an amyloid PET research study (to avoid any confusion over whether the hypothetical results were actually real). Additional eligibility criteria included participants be at least 18 years of age and English speaking. The initial study was approved by the institutional review board of University of Pittsburgh.

Data Collection

Within 6 months of completing the initial study, participants were invited to the focus group with other study participants. The focus group was facilitated by a trained social worker who had not participated in the initial results disclosure and interviews. Two trained research assistants completed field observations and note taking. The focus group session was audio recorded and transcribed by a trained research assistant and was approved by the institutional review board of University of Pittsburgh. The focus group interview guide consisted of 14 semistructured questions with cue prompts that addressed the acceptability, including the clarity and perceived value, of the amyloid imaging results disclosure protocol. These results are previously published (7). Participants also shared their views on the disclosure sessions and discussed their experience of completing a cognitive evaluation resulting in an MCI diagnosis thus providing a rich additional layer to our understanding of participant’s experiences.

Data Coding and Analysis

Qualitative content methodology was used to analyze the focus group data. Frequent research meetings were held to complete line-by-line coding, category generation, and theme identification. When discrepancies occurred, the research team developed consensus in coding by carefully reviewing the text, revising codes or themes, and identifying thematic relationships (8). The study is an analysis of rich and substantive data that the focus group participants provided, beyond the primary goal of offering feedback on the mock disclosure sessions conducted during the initial study. Specifically, this analysis examines, in-depth, participants’ broader perspectives on the process of having cognitive impairment and undergoing its evaluation.

Results

Participants’ Profiles

Ten dyads (patients and care partners) were recruited in the mock disclosure of amyloid imaging result session, and 8 participants were available to participate in the subsequent focus group session. They shared their views on the disclosure sessions and discussed their experience of completing a cognitive evaluation resulting in an MCI diagnosis. Four of the 8 participants were part of patient-care partner dyads. Two participant patients, and 2 care partners, attended the

Table 1. Sample Characteristics.

Variable	Patient (n = 4)	Family Member (n = 4)
Age in years (range)	85-92	76-86
Education		
<HS	0	0
HS/GED	1	0
Technical school or college	3	4
Gender		
Female	0	3
Male	4	1
Race/ethnicity		
Black/African American	0	1
White/Caucasian	4	3
Relationship		
Spouse/partner		3
Adult child		1
MCI subtype		
Amnestic	1	
Nonamnestic	3	

Abbreviations: GED, General (high school) Equivalency Diploma; HS, High School; MCI, mild cognitive impairment.

focus group individually without their study partner. Overall, 8 of the 10 dyads from the initial study were represented in the focus group. Table 1 provides an overview of the socio-demographic characteristics of the focus group participants.

Focus Group Results

The focus group was 1 hour and 43 minutes in duration. When reminded that the purpose of the parent study was to identify the best approach to disclosing amyloid imaging results, participants spontaneously initiated a more general discussion of their perspectives on undergoing, or having their loved ones undergo, an evaluation of cognitive complaints. Recognizing participants' desire to step back and consider cognitive evaluations more generally, the focus group moderator facilitated this discussion by asking questions such as, "What do others think about that?" All 8 participants in the focus group contributed to the resulting discussion. It was noted that when the facilitator later returned to the interview guide, participants continued to report their perceptions of their cognitive evaluations in general terms.

A successfully conducted focus group will create intimacy, meaning the participants talk to each other as well as the facilitator, and participants might safely disagree with each other (9). In this focus group, participants both spoke to each other and the facilitator. At times, participants expressed friendly disagreements indicating the facilitator created an environment in which the participants felt safe. Rich data were found when the participants talked among themselves. Accordingly, the results presented below reflect participants' responses to the initial invitation to share their views about cognitive evaluations, as well as comments that

emerged throughout the focus group as part of the thread of the discussion. Furthermore, several participants shared personal stories as a means to express their perspectives and emotions. Stories may offer a way to provide meaning or may be used as a coping method to create order when in chaotic circumstances (10). One care partner used the word "painful" to describe a story about taking her mother's checkbook away. Another participant told a story about the difficulty of finding support groups for her as a care partner in her rural location.

Participants offered numerous statements expressing a sense of vulnerability, powerlessness, and fear. The general discussion of undergoing, or witnessing one's loved one undergo a workup for cognitive complaints yielded 2 overarching themes (Table 2) that emerged from the data: (1) The "presence of a threat" emerged as an overarching theme related to living with MCI symptoms and living through an evaluation of cognitive complaints. This theme encompassed several subthemes: (a) emotional aspects about various phases of a cognitive evaluation, (b) stigma related to an MCI diagnosis, (c) the short- and long-term prognosis, (d) dealings with the medical establishment, (e) and lack of knowledge about treatment options and coping techniques for MCI. We discuss the participant's emotional reactions and fear of stigma in more detail. (2) The second theme involved approaches participants took to "minimize the threat," and included subthemes: (a) using language to minimize threat, (b) information sharing and withholding, (c) using social support to legitimize experiences.

Presence of a Threat

Emotional reactions. Comments regarding anxiety and other emotions were present throughout the discussion. Perceptions of emotional reactions including anxiety in response to receiving an MCI diagnosis were variable. One care partner referred to the experience as a "punch in the stomach," and went on to express a sense of devastation with the statement, "I thought my world had ended." Although the visceral nature of the experience was echoed by at least 3 participants, this feeling was not shared by all individuals. Offering a counter-narrative, one patient participant stated, "You already know something is happening, you're not being punched . . . you're not being scared because you are just being reaffirmed that something is going on . . ." This last statement suggests that there is a dimension of relief, for some individuals, in receiving the diagnosis. The wide range of responses to receiving an MCI diagnosis is validated by a statement from the facilitator, "People can have really varied reactions to getting the news . . . and to understanding what they are experiencing."

Stigma. The threat of stigma related to cognitive impairment was a specifically named threat that emerged among focus group participants. For example, participants described cognitive impairment as a long-standing source of social stigma.

Table 2. Summary of Themes and Subthemes.

Themes	Presence of a threat	Minimizing the threat
Subthemes	Emotional reactions Fear of stigma	Use of language Information sharing and withholding Use of social support to legitimize personal experiences

One care partner commented, “People didn’t want to talk about it before. It was a social stigma,” which was in reference to how previous generations avoided acknowledging cognitive decline within older members of their families. The same care partner described the profound social isolation of a relative who was nearly abandoned by his family, “. . . [other relatives are] taking care of [him] and not just throwing him away.” Participants also indicated that stigma may be one force underlying the denial of memory symptoms, or resistance to seeking a memory evaluation among some individuals in their peer groups. One care partner commented, “Well they are at the same stage and they are refusing to find out definitively.”

Threat Minimization

The use of language to minimize threat. The participants took several approaches to cope with their fears through the use of language, information seeking or withholding, and through social support. In many instances, the fear of cognitive impairment was vague and unnamed reflecting a possible attempt to distance themselves from the threat. “You are just being reaffirmed that something is going on with you and you don’t know what it is.” This quote exemplifies a pattern that was observed throughout the focus group session. Specifically, the transcript reveals repeated references to “it” suggesting a reluctance, whether conscious or not, to name or label the threat of cognitive impairment. The phenomenon of an unnamed threat is particularly evidenced in the statement, “So I want to know if there is something coming along the way, if I am going to be on that bus to get there,” by a patient participant who refers to a cognitive disorder as “something” and uses the metaphor of travel by bus to represent progression to dementia. An alternative explanation of participants’ indirect references to MCI and dementia is that the threat of cognitive impairment, while unnamed, is well known to this group and that participants were refraining from labeling the threat because of the groups quickly established shared understanding of what it means to live with and be evaluated for cognitive complaints.

Information sharing and withholding. This subtheme encompassed the acts of both acquiring and withholding information related to cognitive symptoms and their implications. Participants expressed a high level of value to acquiring

information as shown in the statement, “I think getting and obtaining information [about brain amyloid status] is important” and also in the statement “. . . I just remember how beneficial that information [in the mock disclosure] was.” Other participants expanded the notion of information as valuable by depicting the knowledge gained through information as powerful—“knowledge is strength”—and even essential, “. . . you need the knowledge.” Another stated, “I am a happier person if I can deal with situations; the unknown is sometimes the hardest.” This suggests that acquiring information serves to equip individuals to cope with the unknown and provide a sense of control.

One exception to this pattern of commentary was a daughter of a cognitively impaired woman who questioned the value of learning her mother’s amyloid status, “. . . so you all have this additional piece of information but how does that fit into what you may or may not do differently for my mom?” Yet, overall participants in this focus group regarded information acquisition as positive, regardless of whether the information obtained was clinically actionable.

Participants in favor of gaining information contrasted their views with others in their social networks. For example, one care partner participant said, “. . . your friends think, if I accept it I have to deal with it, so now I won’t even consider it because I can push it under the rug and I don’t have to deal with it. But me, I’d rather, I want to know everything I can know, because I want to keep my mom going for as long as I can and I can only do that as long as I have information . . .”

In addition to seeking control through acquiring information, there was the parallel element of seeking control through withholding of information. In response to a question by the facilitator regarding having an additional family member at the disclosure session, one dyad emphatically responded “No, no” and we wouldn’t need a third person [family member].” The dyad offered as further explanation, “We want to disclose what we want to disclose,” suggesting that they want to have control over sharing and withholding information about the cognitive evaluation. They added, “Because we don’t know how they interpret it,” indicating a concern that the information about cognitive symptoms, or the evaluation of such symptoms, could be misunderstood or contribute to stigma. Quite possibly, the act of releasing or sharing information is perceived as an act of partially relinquishing control. In as much as participants described acquiring knowledge as a means of gaining control, sharing information may serve a corresponding function of diluting one’s sense of control. Therefore, withholding information is a second means of seeking control.

For other individuals, sharing information was viewed quite differently. One care partner described sharing results of the cognitive evaluation with family members as a means of helping those family members to understand and acknowledge the seriousness of her loved one’s cognitive changes, “. . . they could no longer stick their head in the sand . . .”. Another care partner stated, “. . . I thought it might have been nice to Skype, to have them be part of that

[disclosure session], because we sort of do things as a family unit, even though we're all over the country." For this individual, sharing information served to draw the family together.

Social support and legitimizing experiences. The shared experience of memory loss may help prevent a sense of isolation for participants and help to legitimize their experiences. This was manifested among both participants with MCI and care partners who depicted memory loss as a ubiquitous, age-related phenomenon. This subtheme first emerged when one participant stated that, "And all the literature we've read—and we have read about as much as we could read—... and they are saying that after 65, everybody is certainly experiencing memory loss." This theme continued when the focus group facilitator asked participants about the clarity of the earlier mock disclosure session. The first response to her question was the statement, "None of us remember [the details of the mock]." This theme continued throughout the focus group session. One care partner extended the notion of memory loss as ubiquitous by describing memory loss within her pet, "And we are all realizing that we are all suffering from deficits. I mean, I had a dog that went through this!" This comment was echoed by another participant describing similar symptoms in her pet dog. Participants therefore legitimized their experience through social comparisons, asserting that they weren't alone in their experiences.

Seeking various forms of social support was identified as way in which focus group participants coped with the threat posed by cognitive impairment. Recognizing the degenerative nature of cognitive decline, one patient participant expressed the comfort derived from the knowledge that her family would be there as she became more vulnerable, "... it goes in stages, I want to be able to deal with what I can and have family members, that when I am not able to connect, that they are all part of this scheme." A married couple described having a reciprocal care relationship in late life, "We are going hand-and-hand through it together." Other participants also described the support of those within their immediate social network as playing a key role in prioritizing the needs of their family, "perhaps the family itself is the best identifier of what their needs may be..."

Although many participants acknowledged the importance of social support offered by their family, at least one care partner described seeking support outside the family. One daughter of a participant with MCI stated, "I belong to a support group... it's been the most wonderful thing [to be with] people at the beginning of the road like I am" describing the camaraderie that she found in the company of other care partners.

In addition to statements related to seeking the support of family, friends, and community members in their daily lives, participants also actively sought and provided support to one another during the focus group. This bonding phenomenon was particularly evident in their discussion of their shared

views and experiences of memory loss as a normal aging process. Reflecting group intimacy, there are multiple instances of shared laughter and validation of each other's perspectives and experiences. Signaling the sense of solidarity, there are multiple instances that participants used a collective voice to describe themselves as a group, for example, "we all take fish oil!" followed by laughter. Another participant also stated, "I think we, all around the table, want to be best informed about ourselves and our loved ones as we can."

Discussion

The aim of this analysis was to characterize the subjective experience of seeking an evaluation for, and receiving a diagnosis of, MCI. The presence of a threat included 2 subthemes, emotional reactions and the theme of stigma. Mechanisms for reducing and coping with the threat comprised 3 additional subthemes of the analysis, threat minimization using language, information sharing and withholding, and using social support to legitimize their experiences.

Presence of a Threat: Unknown Prognosis, But Known Stigma

Our findings regarding perceptions of threat and the related construct of fear are consistent with those reported in other qualitative studies examining patient and care partner perceptions either before or after receiving a diagnosis of a cognitive disorder (2–4,11–14). Our analysis added to this body of knowledge in revealing that threat of the unknown was specifically expressed when a patient or care partner noticed memory problems for which they (a) had been offered no clear explanation, and (b) harbored uncertainty about addressing. In the MCI population specifically, previous qualitative research has shown that uncertainty and fear can emerge not only in response to current symptom burden but also in association with a patient's prognosis for the future (15).

In terms of the threat of stigma, our findings are consistent with extensive evidence in the published literature on the experience of having cognitive impairment (16–23, 24). Like other psychiatric and neurological disorders, dementia and cognitive impairment have a long-standing historical association with the lay concept of "madness" and in some instances criminality. Our findings support the notion that concerns about stigma can occur even in the earliest stages of cognitive impairment.

Maintaining Control and Minimizing Threat

A common way to minimize the emergent threats related to MCI was through seeking control of information. Following a diagnosis, individuals typically express interest in obtaining information related to the severity of the disease, the

prognosis, and possible treatments (4,14,15,25). Extending the findings of recent literature, our data also revealed another aspect of seeking control through the withholding of information. When asked about having a third person, such as another family member, participate in the diagnostic disclosure session, one dyad in our study responded that they did not want a third person involved. Although this response was not shared by other members of the focus group, it does suggest possible underlying concerns about stigma. This dyad expressed concern about a loss of control of the information shared and concerns regarding interpretation of the diagnostic information.

Seeking social support was identified as an additional strategy to minimize threat. Participants in our study sought support from their family members, friends, and social support groups. Two recent review studies have reported that support groups were very beneficial to patients and caregivers by supporting them as they faced stigmatization and by providing information related to adjusting to life event changes (26–28). These findings were also evident in our data.

Participants legitimized the experience of memory loss by associating memory changes with normal aging, supporting findings from previous studies (13,15,29,30). Hinton and Levkoff have reported that individuals may delay seeking a cognitive evaluation because symptoms were normalized (31). However, even after patients received the diagnosis of MCI, they still viewed their memory loss as a ubiquitous phenomenon among older adults. On one hand, this finding might suggest participants were in active denial of their diagnosis and coped by normalizing their problems. Alternatively, normalization of memory symptoms could suggest a lack of awareness or knowledge related to MCI.

From a clinical practice perspective, our study has several implications. Patients and care partners placed a high value on knowledge and information regarding MCI. However, clinicians when providing this information should understand the sense of threat or fear a person newly diagnosed with MCI or their partner may have and the different ways they may cope. Gathering extensive information about MCI may be a form of control over their diagnosis, while at that same time, patients must also cope with a threat of stigma. Having a conversation with patients and care partners about whether (or not) there are loved ones they would like to include in the discussion session may be beneficial.

Limitations

There were several limitations in our study. First, the sample was drawn from an ADRC, which may not be representative of the general population. Second, both care partners and patients participated in a single focus group to share their views about cognitive evaluation, which may give a mixed view of affected patients and family members. Future studies should explore patients' and care partners' perspectives

separately to determine whether differences in perception exist. Third, the focus group was conducted after patients completed cognitive evaluations and received an MCI diagnosis. Patients' and care partners' views are captured at one particular time after the opportunity for reflection on the assessment process could occur. A more continuous picture of the perceptions related to assessment and diagnosis is needed. Longitudinal studies that collect narratives before the cognitive evaluation, shortly after the evaluation, and at a later time may provide a more comprehensive picture of the MCI experience. Fourth, the sample was limited in that not all the participants who participated in the mock disclosure sessions were able to attend the focus group. These missing perspectives may have provided additional insight not described here. Fifth, the participants were white and highly educated; thus, future studies on this topic should include the perspectives of a more diverse population.

Conclusion

This analysis builds on previous work exploring how patients with MCI and their care partners view and cope with the threat of MCI during the cognitive evaluation process. These findings may inform how assessment and diagnostic disclosures are conducted, particularly when newly developed biomarker technologies are incorporated into the evaluation protocol. Continued focus on subjective perceptions of cognitive evaluation is especially critical as diagnostic processes evolve and more individuals in the mild stages of cognitive impairment are seeking assessment and an understanding of the cause of their memory concerns.

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