

“Nobody Likes to Admit What’s Going On”: Avoidance Behaviors of Families Coping with MCI

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Introduction

Managing stress using avoidance coping strategies allows family members to manage their emotional responses as well as cope with changes in their relative’s memory, behavior, and sociability that manifest with mild cognitive impairment (MCI). The purpose of this study is to examine the use of avoidance coping behaviors by identifying conditions preceding an avoidance response and specific types of avoidance strategies used to cope with stresses of having a relative with MCI. This investigation is guided by Lazarus and Folkman’s (1984) conceptualization of avoidance coping behaviors. Data analysis used Strauss and Corbin’s (1990) method of constant comparison.

Methods

Semi-structured, open-ended interviews conducted with 99 families living in southwest Virginia and recruited through local memory clinics.

Family participants

- Elder (age 60+) has MCI
- Primary care partner (PCP) (e.g., spouse, other relative, or friend)
- Secondary care partner (SCP) (e.g., relative or friend)

Study focus

- Knowledge about MCI
- Awareness of elder’s needs and condition
- Coping with challenges related to elder’s condition

Findings

Of the 99 families, 35 families reported using avoidance coping strategies to cope with the elder’s condition and the challenges introduced by MCI.

Participant Characteristics (n = 38)

- 90% female
- 28-82 years of age (M=58.4; SD= 13.8)
- Relationship: 48% spouse; 45% child; 3% grandchild
- Proximity from elder: ≤15 miles = 53%; ≤ 60 miles= 73%; ≥ 100 miles = 20%

Use of avoidance coping strategies

- Not associated with age, relationship, proximity to elder, or care role
- Influenced by family expectations and intrapersonal relationships
- Increased among PCPs when caregiving stress increased
- Decreased among SCPs when awareness and acceptance increased

Categories of avoidance coping strategies

- Planned, Unplanned, or Imposed

Planned Responses

The majority of respondents using avoidance behaviors were deliberate in avoiding interactions with their elders. They used one or more of the following strategies:

MAINTAINING DISTANCE

Respondents chose to distance themselves from the person or situation that had the potential to generate conflict.

I took over my son’s room upstairs, put a television in it, put my own heater/air conditioner in there so I could smoke my pipe. ~ PCP, husband, age 67

I learned to keep myself busy [away from him] to close out a lot of things that make me unhappy. ~ PCP, wife, age 60.

DENIAL

PCPs and SCPs were candid about being in denial about the elder’s condition.

Up until now, I think I have just been hiding, hiding in the sand! Well, you know, I just didn’t want to think ...you know, we’ve been together for 10 years, and I’m not ready to think life is gonna change. I’m not ready for that. ~ PCP, wife, age 59

I guess I keep thinking it’s going to level out and he’s going to always be at this stage. ~ SCP, son, age 49

BLAME

SCPs blamed a parent for exaggerating the severity of the elder’s cognitive impairments.

Mom is making more “to do” of it than it really is. ~ SCP, daughter, age 54

FATE

One PCP decided to allow fate to drive the course of her future interactions with the elder.

I am not going to deal with it. It’s like if it’s going to happen, it’s down the road. So, don’t think about it, don’t worry about it. ~ PCP, wife, age 52

Unplanned Responses

Respondents reported taking advantage of unplanned opportunities to help manage their stress. Over time, however, as daily stress mounted they began to rely on the unplanned opportunities as a way to distance themselves from the elder.

OPPORTUNITY

We do a lot of house projects, I do a lot of yard work. I like to do that. At times I find excuses [to stay at home] and not visit her. ~ PCP, daughter, age 53

Imposed Responses

SCPs, who are adult children, reported that despite their willingness to provide support, their actions were constrained by pressures imposed by family members to act differently. Pressures resulted from three family notions:

DENIAL

SCPs were challenged by family fronts of denial that prevented any discussion of the problem.

When he first started showing signs of dementia, I had brought it to her and everybody else’s attention in the family and I guess the first 1 ½ years everybody just blew it out the window because nobody likes to admit that’s what’s going on...until they are ready to hear it, it isn’t going to make a bit of difference. ~ SCP, daughter, age 53

RESPECT & DEFERENCE

SCPs felt obliged to respect the elder’s and PCP’s autonomy and show deference for their lifestyle choices.

Until last year, they cared for each other. They filled the gaps for each other and then that was another issue. Dad was not eating like he should because mom was not cooking like she should have been and here again, we probably sort of chose to ignore that. That’s hard. ~ SCP, daughter, age 60

SILENCE

Elders and PCPs stonewalled attempts by others to gain understanding and provide support by remaining uncommunicative.

It’s like he’s scared to carry on the conversation. I guess he’s afraid of what he might say or might not say. So he just shuts down. He has no interaction. ~ SCP, daughter, age 51

I wanted to know...but because of her secrecy she would never share it. If wishes were horses, beggars would ride. ~PCP, husband, age 67

Conclusions and Implications

Individuals and families that use avoidance coping strategies reported relief and reduced feelings of responsibility as long as the elders’ health and behavior did not require different action. Individuals recognized that avoidance coping placed elders and care partners at risk for poor health outcomes and reduced quality of life, yet continued out of self-interest.

Future research needs to

- Include family relationship dynamics and group emotional health when addressing the caregiving process
- Examine the repertoire of avoidance coping strategies used by family members and the influence of each on provision of support

Application of findings for practice include

- Acknowledging the influence of family dynamics on caregiving
- Including family members in discussions of support