

Caregiver Competence to Prevent Home Injury to the Care Recipient with Dementia

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KEY WORDS

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dementia
home safety caregiving

Home safety is a major concern for persons with a progressive dementia, such as Alzheimer's disease, because much direct care is provided in the home setting. This study used the Home Safety/Injury Model as a framework to describe the domain of caregiver competence, one of the model's key constructs. Interview data from the perspectives of 17 informants yielded a total of 68 clinical situations that allowed exploration of the scope and dimensions of caregiver competence to prevent accidents in the home. The factors most influential for effective caregiver prevention of home injury were family support, an acceptance and ability to make role changes, teaching and role modeling from professionals, and long-standing values and family traditions. No single factor was sufficient to achieve effective caregiving for making the home safer, but the strength of one or two factors could compensate for the absence of others.

Alzheimer's disease is the most common of several progressive dementias that cause cognitive and functional decline and, ultimately, death (Klein & Kowall, 1998). The Alzheimer's Association (2004) estimates that 14 million Americans will have Alzheimer's disease by the year 2050 if preventive measures and a cure are not found. Persons with Alzheimer's disease or a related dementia may require many years of home and community care directed toward maintaining independence, preventing progressive disability and deconditioning, and ensuring safety (Hurley, 1996).

Home safety is a concern for all persons with dementia of the Alzheimer's type (DAT). Injuries from accidents are a leading cause of death in the elderly population (Lilley, 1995), and the likelihood of injury is increased with cognitive impairment (Langlois et al., 1995). Cognitive symptoms that affect safety are memory loss, inability to reason, and poor judgment. The person with dementia cannot recognize a safety hazard, has lost the capacity to make good judgments, cannot call for help, and may have a movement as well as a memory disorder. These factors all predispose individuals to injury.

To date, the focus of safety interventions in dementia care has been to prevent the afflicted person from driving and from getting lost (Algase & Beattie, 2001; Cotrell, 1999; Logsdon, 1998; Melillo & Futrell, 1998; Reinah, 1997; Silverstein, Flaherty & Tobin, 2002). Very little research has been conducted on safety hazards and home modification. Through review of the literature and almost 20 years of clinical practice for dementia caregivers, the authors developed the Home Safety/Injury Model (Figure 1) to guide research and clinical practice (Hurley et al., 2004).

The overall goal of the Home Safety/Injury Model is to decrease the risky behaviors and reduce safety hazards that can lead to accidents and injuries in persons with dementia living in the home environment. A program of research has been undertaken to test systematically the concepts and relationships of the Home Safety/Injury Model. The purpose of this study was to explore and describe the domain of caregiver competence, one of the key constructs of the model. A qualitative design was used to answer the following research questions:

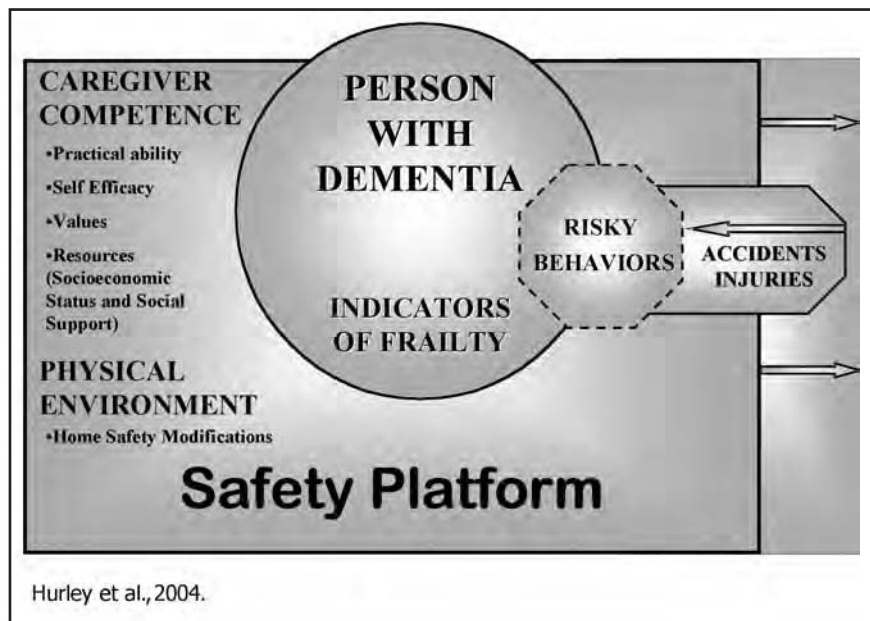
- What are the scope and dimensions of caregiver competence to prevent home injury for a person with DAT?
- What factors contribute to caregiver competence?
- What are the ranges of less effective to more effective caregiver behaviors used to manage a care recipient with DAT at home?

Home Safety/Injury Model

The Home Safety/Injury Model (Figure 1) guides interventions to prevent injury by providing an environmentally safe home living situation for the person with dementia and by giving the caregiver the knowledge and self-confidence to prevent risky behaviors that lead to injuries. The model consists of three main components: (1) the person with dementia, whose condition is influenced by disease and age-related frailties; (2) the safety platform, which includes the concepts of physical environment and caregiver competence; and (3) risky behaviors of the person with dementia, which may lead to negative outcomes if the safety platform is inadequate.

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Figure 1. Home Safety/Injury Model



The combination of the physical environment and caregiver competence forms the safety platform for the patient. When the safety platform is adequate, the risky behaviors of the person with dementia are contained within the platform, and the potential for accidents and injuries is reduced, as indicated by the arrows pointing to the left in **Figure 1**. If the risky behaviors extend beyond the safety platform, accidents and injuries can occur. However, extending the safety platform, as indicated by the arrows pointing to the right in **Figure 1**, can contain the risky behaviors again and reduce the likelihood of accidents and injuries.

Caregiver Competence

Caregiver competence has been defined as the effective performance of caregiving tasks, including the actions associated with the care recipient's safety and the related knowledge and skills (Kosberg & Cairl, 1991). This definition is consistent with our initial conceptualization of caregiver competence as having two essential elements: practical ability and self-efficacy.

Practical ability means that the caregiver has the knowledge and skills to make safety modifications and to minimize safety hazards that cannot be changed. Lach and colleagues (1995) found that safety problems occurred at all stages of DAT, with wandering, driving, and cooking being the most common problems. They reported that barriers to making home safety modifications were that caregivers did not know ways to prevent accidents or where to obtain helpful information.

Even in the presence of adequate skills, however, a person's perception of low self-efficacy (judgment about his or her ability to perform a task) can interfere with achievement (Bandura, 1997). In this model, this dimension of caregiver competence is based on self-perceptions of one's abilities as a caregiver. If individuals believe they are capable of performing specific behaviors, they are more likely to do so. In recent studies, self-efficacy beliefs have been shown to motivate elders in a rehabilitation program and after stroke recovery (Resnick, 2002; Robinson-Smith, 2003). Gitlin and colleagues (2001) found a significant difference in self-efficacy between intervention and control groups of DAT caregivers following a home environmental intervention that included five home visits by an occupational therapist.

Values and resources also influence caregiver competence in the Home Safety / Injury Model because these factors direct and support caregiver actions. Values influence behavior because they represent what is important in one's life. Resources comprise both socioeconomic status and social support. The amount and adequacy of resources modulate practical ability and self-efficacy by providing tangible support to cope with the tasks of caregiving.

Study Methods

This study used a descriptive, exploratory design to understand the domain of caregiver competence and to answer the research questions. Methods from both interpretive phenomenology and constructivist grounded theory were employed, which allowed for interpretive means to understand the data while using many of the tools of grounded theory for data analysis (Benner, 1994; Charmaz, 2000). (A full discussion of the premises underlying interpretive and constructive paradigms is beyond the scope of this article, and the interested reader is referred to Schwandt [2000]). In recent years, the similarities of these paradigms for a practical understanding of human beings and action have been recognized (Lincoln & Guba, 2000). The research process in this study was designed with the goal of grounding the concept of caregiver competence in the realities of everyday life and presenting a convincing story for clinicians for whom the question of environmental safety in DAT is important (Miller & Crabtree, 2000).

Sample

The researchers identified a purposive, theoretical, sampling plan to interview interdisciplinary professionals from diverse settings who were key informants with experience in supporting caregivers of persons with dementia living at home (Silverman, 2000). A sample of professional caregivers, rather than family caregivers, was used to obtain a

broad, but realistic range of home safety situations and variations in caregiver actions. Seventeen professional caregivers described a total of 68 patient care situations of safe and unsafe home environments and ranges of effective to less effective caregiver safety behaviors.

The informants worked in public agencies ($n = 11$) and in private, not-for-profit agencies ($n = 6$). The types of living settings included dementia clinics, elderly housing, home care, and senior centers. Eleven of the informants were female, and 6 were male; 14 of the informants were White and 3 were Black. Informants represented the disciplines of nursing, social work, occupational therapy, and housing and home care administration.

Procedures

A semistructured interview was developed with questions to elicit descriptions of clinical situations that represented the continuum of unsafe to safer home environments and less effective to more effective caregiver behaviors to promote safety. Informants were asked to describe actual patient stories with rich situational details to help the investigators understand the practical realities of providing a safe home environment for a person with DAT. Focusing on actual patient situations is a strategy to help avoid global generalizations or opinions about the domain of interest and, instead, capture the complexities and nuances of everyday practice (Benner, 1994). This strategy also assisted the researchers in being open to the data and instances where preconceived notions were challenged, refuted, confirmed, or extended.

Several iterative processes common to many qualitative designs were used to support the credibility of the data analysis: concurrent data collection and data analysis; constant comparison of similarities, differences, parts and the whole of the text; repeated access to the informants; search for atypical cases; repeat analysis by more than one investigator; with dialogue to resolve discrepancies; and sharing of the interpretations with some informants to determine whether their meanings had been captured fully (Benner, 1994; Miles & Huberman, 1994; Patton, 1999; Silverman, 2000). Interviews were audiotaped, transcribed and entered into ETHNOGRAPH 5.7 to assist with the analysis.

Findings

Stories about caregivers and home safety for persons with DAT described family members who were unaware of potential safety hazards in the home and how to modify them, but just as importantly, who were unaware of the nature of the illness with which they were dealing. Understanding the progressive nature of dementia and its effect on memory, judgment, and behavior was necessary before the

caregiver could appreciate the actions needed to make the home environment safer. Often, risky behaviors leading to accidents were the first sign to caregivers that there was a need for change to protect the person with DAT from injury.

Caregiver Knowledge and Skills

The most serious environmental hazards about which caregivers needed knowledge and skills were unsecured exits; unsupervised access to the stove, knives, and medicine; and obstacles in walkways and on stairways. Accordingly, the most prevalent risky behaviors that led to accidents and injuries in home environments were wandering, cooking, taking medication, and walking. Informants frequently described using the stove and leaving the home unsupervised as risky behaviors with the potential for serious injury to the person with DAT and to others, especially in the case of fires. Leaving a pot on the stove and not realizing what to do when the apartment got smoky often were early signs to others that the person was not able to manage living at home alone. One informant related the following story:

I can give you a recent example, a woman who's a long-time resident of our housing started to exhibit symptoms of confusion. Suddenly she would not have her keys or other little things, and the other residents were concerned. So I talked to her and felt there was something going on and thought, what do we need to do? Her appearance was fine, well groomed, never needed home care services to this point. Right after I spoke to her, she left the apartment with something on the stove and set the apartment on fire. It became quite evident that she didn't understand that it was serious. When we cleaned up the apartment, we noticed that it was loaded with bags, boxes, all kinds of clutter. At that point we knew she needed home care. She didn't understand the severity of what she'd done, and the other residents were at risk.

When the person with DAT is living alone, as in the situation just described, there is no one who sees the subtle, early changes in cognitive and functional performance. The first signal to others of her cognitive impairment was a significant safety hazard. Even in families where there was a beginning knowledge of dementia and safety issues, however, it often took a serious safety incident to motivate the family to seek help and make environmental changes. As one informant stated:

Very often, there was a catastrophic event or some kind of a crisis or nearcrisis. Sometimes, somebody else noticed the problem, but if nothing serious had happened yet, the family was more resistant, less willing to make changes.

Supportive networks of people who are willing to work with the patient in the lengthy process of rehabilitation from pain are very important.

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The most unsafe home situations had multiple safety hazards, as illustrated in the following excerpt:

I remember seeing right away that the knives were out. Whether or not he would have picked up the knives, I don't know, but they weren't in something—you could see the knives. It was like a display. And there was a porch, and he could just walk out and you wouldn't even know it. There was a screen door, and there wasn't any latch on it.

In this situation, the caregiver's knowledge and skills were severely limited by her fear of confrontation with her spouse with DAT. She did not want her husband to know that the "visitor" was a home health nurse because of her fear of his anger at a stranger coming in to the house. The prior relationship between this couple and the husband's pre-morbid personality are unknown factors in this case, but might have influenced the dangerous stalemate observed by the home health nurse. From a societal perspective, this family has not had adequate access to or utilization of healthcare resources to diagnose and treat the behavioral consequences of DAT.

If caregivers knew someone who had DAT or their caregivers, they were more likely to seek information. By contrast, general care-giving experiences with disabled or chronically ill family members did not influence caregiver behaviors to seek information about DAT and safety issues. In families where there was prior knowledge and/or experience with DAT, the caregivers had contacted the Alzheimer's Association and had information about the Safe Return program and strategies to prevent wandering outside alone. Nevertheless, accessing information was not synonymous with using it. When caregivers got overwhelmed, they would not remember the recommendations, which often were given during a too-brief clinical encounter. Also, caregivers needed instruction in behavior management techniques to implement safety recommendations, as this anecdote illustrates:

I don't think she understood some of the things that I talked with her about because she was so overwhelmed, she didn't hear me. I think I tried to give her too much information, but I had just a short period of time. Then she was saying that she has to go out and he [care recipient] wouldn't agree to have someone stay with him. I told her he couldn't make that decision now, but she said he was a very bright man, a teacher. The family had a hard time realizing the person was no longer competent to make decisions. And they said, 'He was always like this; he was always stubborn.' So, the teaching can be difficult. I try to

model behaviors when I am there, like how to divert behavior instead of saying 'no' so much. [rather] '(Oh, you want to go outside? Great, I want to go outside, too. Let's just have something to eat before we go.'

Family members in this situation had to revise their understanding of the patient's capacities within the context of having a disease that causes cognitive impairment. Making safety decisions often involves a shift in power relations in the family because the afflicted person now has a problem with judgment as well as memory. Addressing the nature of the illness and its meaning for family communication and decision-making was a prerequisite to teaching about home safety. The economic demands on healthcare professionals to generate volume in patient encounters, however, can limit the available time for assessment and counseling families to support them in this transition.

Effective Caregiving

The factors that were most influential for the effective performance of caregiving tasks to prevent home injury were family support, an acceptance and ability to make role changes, teaching and role modeling from professionals, the prior relationship between the caregiver and the care recipient, and long-standing values and family traditions. The factors were equally important, depending on the specific situation, and they often blended in various combinations that influenced effective caregiving. In the numerous examples described, no one factor alone was sufficient to achieve effective caregiving and a safer physical environment. Sometimes, the strength of one or two factors would compensate for the absence of others.

The following excerpt describes a man who cared for his wife for many years with no prior experience in caregiving and no concrete family assistance. Through an alliance with the nurse, his strong family values, and his willingness and ability (resilience, perhaps) to cope with the demands of the situation, the care recipient was able to remain at home for 11 years despite the caregiver's initial lack of knowledge and skills.

I don't remember anything that [the caregiver] didn't do that we told him to. Her dementia was far gone but he really loved her and didn't want her in a nursing home. His family lived right next door—his brother and his sister-in-law. [After] his wife became ill, they didn't have any contact with her, but they would allow him to come over and visit. So that was really sad and strained for him. In my relationship with him, he seemed to truly trust

Table 1. Examples of Self-Efficacy Sources in Home Safety Modifications

Source of Self-Efficacy	Home Safety Examples
1. Enactive mastery	"I used that concealed bolt lock to prevent him from leaving the house alone during the night; since I succeeded there, now I can..."
2. Vicarious experience	"Mrs. Y is a lot like me and she is able to..., so can I."
3. Verbal persuasion	"Mrs. Z told me to do... and she has been right in the past, so if she says I should do it, I know I can..."
4. Physiological state	"My heart was racing when I heard him at the stove, now I know I have to cover the knobs so he can't turn it on."

that everything I was telling him was the right thing to do. I think I was an authority figure and that he also saw that the [advice] worked.

This excerpt illustrates the potential to enhance self-efficacy, one of the postulated concepts that contributes to caregiver competence. Although there is no direct evidence of this caregiver's perceptions of his ability to maintain home safety, the four sources of self-efficacy are represented (Bandura, 1997; **Table 1**):

1. *Enactive mastery* is based on an individual's own successful experience and is considered the most influential source of efficacy information.
2. *Vicarious experience* occurs when individuals view others as models and compare themselves with the observed experience.
3. *Verbal persuasion*, being encouraged to do something, is related to the recipient's confidence in the person who gives the direction.
4. *Physiological state*, when people identify their state of arousal on the basis of somatic symptoms, can alter the level of self-efficacy.

The situation of the husband who cared for his impaired wife illustrates sources of self-efficacy beliefs. Through the *verbal persuasion* on the part of the nurse, the caregiver's confidence in her advice, and the *vicarious experience* of watching the nurse provide care, the caregiver begins to have some success in managing his wife at home, which reinforces through *enactive mastery* his perceptions of himself as effective. The caregiver is effective despite the lack of family support. Taken together, the trust, learning, and collaboration with the nurse compensated for the caregiver's initial lack of practical ability. In fact, the caregiver's determination to keep his wife at home because of his values and traditions appears to be the driving force in his success. His story can be understood on the basis of social-cognitive theory, which posits a multifaceted causal structure in which self-efficacy beliefs operate together with goals, outcome expectations, and perceived environmental impediments and facilitators in the

regulation of human motivation, behavior, and well-being (Bandura, 2004).

Gaps in Supervision

Despite caregiver knowledge and skills and home safety modifications, times when a patient is unsupervised presents opportunities for accidents and injuries to occur. The problem persists and is exacerbated when caregivers do not notice the early signs of dementia, do not understand the nature of the illness, and are unaware of or have few options. As one informant stated, "It's hard for people because their whole lives are changing."

In the next excerpt, the informant described a situation that was characteristic of many families who were trying to accomplish multiple caregiving tasks. If the caregiver had to work, especially adult children of the care recipient who also cared for children of their own, there was more difficulty finding help to provide all the supervision needed.

One caregiver lived with her mother, but she had to work and her mother did leave the stove on and burned a pan. It was one of those situations where they knew she was impaired, but they didn't really feel they had other options and they took chances.

Even when caregivers think they have adequate supervision, a plan can have gaps in the transition from one resource to the next. In the next excerpt, the caregiver is trying to provide supervision all the time—in this case, using an adult day health center and friends.

The friend expected the daughter home a little earlier and wouldn't have dropped her off if she knew the daughter wasn't going to be there soon. She [care recipient] started something on the stove and went off to play with her cat and left the pot burning. When her daughter came home, it was all smoky but not enough to set the house on fire.

These excerpts illustrate the potential to blame family caregivers for inadequate supervision of the person with DAT when, in fact, community awareness and resources to assist families are limited. This

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family was fortunate to have at least some adult day health services available and, presumably, affordable. In many communities, there are no such services or none with the supervision needed to maintain safety for people with DAT. The desirability of home care by all stakeholders notwithstanding, the family has absorbed the overwhelming responsibility of providing safe care for the person with DAT.

Discussion

Without an awareness of the changes that accompany cognitive impairment, teaching about home safety and other behavior techniques is difficult. To apply safety knowledge effectively, caregivers must understand the nature of the illness and the changes that affect patient autonomy and decision-making. Respecting patient preferences in DAT can be difficult when those choices are unsafe because of impaired judgment. In situations where a person with DAT begins to behave in uncharacteristic ways, the goal of providing a safe environment becomes even more complex and challenging. For example, the caregiver may need to use different strategies to convince the person with DAT to bathe where the experience of bathing has become frightening for the care recipient (Mahoney, Volicer, & Hurley, 2000). The concept of practical knowledge and its contribution to caregiver competence in the Home Safety/Injury Model, therefore, has to include both an understanding of the nature of the illness as well as knowledge about safety hazards.

The influence of the concept of “resources” on caregiver competence initially was conceived as socioeconomic resources, particularly, family support. Family support was a factor that influenced effective caregiving for home safety; however, a lack of family support could be compensated for with other factors, such as trust and continuity in a relationship with a professional. This study suggests that a broader societal context regarding the distribution and access to healthcare resources is significant. Often health professionals are economically constrained from spending sufficient time assisting a family with the multiple and progressive transitions that DAT requires that can lead to increasing safety hazards. Some communities may have more available options to assist families in their efforts to maintain safety. Further research is needed to determine whether place of residence, education, and income affect a family’s access to and utilization of healthcare services for diagnosis and treatment of DAT and safety hazards.

Maintaining close supervision of the person with DAT is as important as making environmental modifications, even for the most knowledgeable

and effective caregivers. Community and family resources give caregivers more options to prevent gaps in supervision and may be not only the most important home safety “modification” but also the one that requires both persistence and creativity by both professional and family caregivers. Adult day health programs are one of the most important sources of supervision for persons with DAT, which provide socialization and meaningful activities for the person with DAT as well as a short respite when caregivers may complete other personal and household tasks.

Some caregivers received information from the Alzheimer’s Association, especially regarding strategies to prevent wandering outside the home; the extent of compliance with the recommendations needs further study. Are the recommendations understood and accepted by families? Are they willing to implement them—why or why not?

A few clinical situations provided evidence of the four sources of self-efficacy, however, this concept and its contribution to caregiver competence needs further study. Physiological state appeared to be an important catalyst for the other sources of self-efficacy when the caregiver’s level of arousal was too low to take action. Caregiver readiness to make home safety modifications was often catalyzed by a critical incident. At the other extreme, high anxiety about behavioral changes associated with DAT interfered with both caregiver learning and self-confidence to implement changes. Bandura (1997) notes that physiological arousal can have a curvilinear effect on self-efficacy, where either too low or too high arousal can interfere with performance. Self-efficacy is domain-specific, and requires description of the gradations and circumstances that affect performance to develop adequate measurement tools.

The findings of this study have some limitations for application to caregivers of persons living at home with a progressive dementia. The study was conducted in one geographic region (Northeast) of the United States and it may not reflect social and cultural traditions in other locales. In addition, all key informants spoke English, therefore, the findings cannot be generalized to non-English-speaking populations.

Implications for Practice

Family caregivers need information and support to navigate the many changes in the home environment that are required to provide safety for the person with DAT. There are several resources that will help clinicians to maximize the time available in a clinical encounter. When families need a better understanding of the progressive nature of cognitive decline in DAT and the unpredictable pace and

nature of behavioral changes, one of the most useful resources is a support group. These groups are run by agencies, such as local councils on aging, state chapters of the Alzheimer's Association, and healthcare facilities. For caregivers who are reluctant to attend a group meeting, there are excellent videos available about the nature of DAT and its impact on the family that could be viewed at home or during a clinic visit. The therapeutic goal is for the family to learn that they are not alone in coping with the illness and that there are treatments that can help, if not cure, the illness.

Depending on the primary caregiver's readiness to learn, the most important safety issues to address are unsecured exits; access to the stove, knives, and medication; and obstacles that could cause tripping or falls. Because of the prevalence of accidents at the stove—especially leaving pots unattended—fire safety also is a primary concern. Pamphlets on home safety are available from the Alzheimer's Association, but the information needs to be reviewed with the caregiver to ensure it is understood and to help them focus on the most important safety issues first.

Despite home safety modifications, a caregiver needs assistance to plan for close supervision of the person with DAT. A referral to social services will help identify family and community resources that can support the caregiver in the effort to close the gaps in supervision. Family counseling is helpful to support caregivers to make the role changes that are eventually and inevitably needed as the person with DAT loses cognitive and functional abilities.

Education programs for nurses and other providers that include both tools for early screening and strategies to address the challenging behaviors of DAT will contribute to a family caregiver's competence to provide a safe home environment. As the American population ages, the incidence and prevalence of DAT will increase. All nurses and other healthcare professionals who care for the elderly will be in a position to notice early signs and symptoms of DAT and refer families for diagnosis and treatment. Role modeling by the nurse or other healthcare professional can be a very effective strategy to teach caregivers how to introduce safety modifications in a way that preserves the afflicted person's dignity and does not provoke anger.

Summary

Caregiver competence to prevent home injury to a person with DAT is interwoven with their understanding of the nature of the disease, the impact on the individual and family, and the illness trajectory over time. Family caregivers need information about home safety hazards and corresponding home safety modifications that is focused on the most frequent and serious risks for injury: unsecured exits; access

to the stove, knives and medications; and objects that could cause falls.

This study provides strong support for the contribution of practical knowledge, values, and resources to the construct of caregiver competence in the Home Safety / Injury Model. The concept of self-efficacy requires more research with a different study design to confirm its contribution to caregiver competence.

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