Characteristics and Underlying Meaning of Hoarding Behavior in Elders With Alzheimer’s Dementia: Caregivers’ Perspective

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ABSTRACT

Background: Dementia and its associated problem behaviors remain bothersome to family and professional caregivers. Exploring characteristics and the underlying meaning of disruptive behaviors in elders with Alzheimer’s dementia can be a first step to pursuing patient-centered care. Although hoarding is relatively harmless, unattended excessive hoarding can create health and safety issues for both patients and caregivers.

Purpose: This study examined the characteristics and underlying meaning of hoarding behavior among Taiwanese elders with Alzheimer’s dementia from the perspective of family caregivers.

Methods: We used an exploratory research design and purposive sampling. A total of 12 family caregivers of elders with Alzheimer’s dementia received qualitative interview. We used one-on-one in-depth interviews to collect data and content analysis to analyze data.

Results: Three main characteristics related to hoarding behavior emerged from the data were “influence of former and current symptoms,” “recurrence of the original personal characteristics and habits,” and “re-experiencing past economic crises.” These three characteristics reflected patients’ past social and family background and the current life situation. We elicited “a desire for security” as the underlying meaning of hoarding behavior.

Conclusion: Findings of this study provide a reference for family and professional care providers to understand dementia-related problem behaviors. Improved caregiver understanding of dementia patient behaviors may help improve caregiver-patient interaction and communication and help caregivers better meet patient needs.

KEY WORDS: Alzheimer’s disease, dementia, hoarding behavior, security needs, elders, caregivers.

Introduction

Approximately 6.7% of people who are 65 years of age and older in Taiwan have dementia (Taiwan Alzheimer’s Disease Association, 2012). Given continued growth trends in the elderly population, the number of elders with dementia is expected to double by 2026 (Taiwan Alzheimer’s Disease Association, 2012). Alzheimer’s disease (AD) is the major cause of dementia in community studies of Chinese and Western populations (Fuh & Wang, 2008). Behavioral and psychological symptoms in dementia (BPSD) are often difficult to handle. Behaviors such as agitation, aggression, repetitive behavior, sleep disturbance, and hoarding can be severely distressing to family caregivers and tax their abilities to care for AD patients, often becoming a key reason for institutional placement (Fuh, 2006).

It is estimated that 70%—90% of AD patients exhibit some degree of BPSD (Chang, Chen, & Lin, 2008; Chiu, Chen, Yip, Hua, & Tang, 2006). Behavioral changes challenge formal and informal caregivers. One study reported that 25% of professional caregiving stress is derived from patients’ disruptive behaviors (Chang et al., 2008). Patients with high-demand disruptive behaviors pull staff away from caring for others in need (Kovach, Noonan, Schidt, & Wells, 2005). Therefore, managing symptoms and behaviors in dementia patients may improve quality of life for patients as well as caregivers.

Rather than being irrational, BPSD may reflect underlying unmet needs. Algase et al. (1996) developed a need-driven dementia-compromised behaviors (NDBs) model to recognize that problem behaviors occur because of patient inability to make her or his needs known to the caregiver. Therefore, behaviors can be seen as attempts for communicating inner distress in the face of unmet needs (Algase et al., 1996). If behaviors are treated as meaningful indicators of unmet needs linked to past experiences, then
knowledge of both a patient’s past experiences and his or her present situation can assist caregivers to understand problem behaviors. Caregivers unable to understand BPSD or determine the underlying causative factor of a particular behavior are less able to intervene (Kovach et al., 2005). Thus, the components relevant to behavior and its underlying meanings must be understood before instituting an intervention.

A survey conducted on dementia-related symptoms and behaviors in Japan found hoarding behavior to be very common (Onishi et al., 2006). Other researchers have reported that nearly half of all elders with dementia exhibit hoarding behavior (Huang, Tsai, Yang, Liu, & Lirng, 1998; Marx & Cohen-Mansfield, 2003). Hoarding has been defined as the acquisition of and failure to discard large amounts of possessions that are useless and valueless (Frost, Hartl, Christian, & Williams, 1995).

In most cases, hoarding is relatively harmless. However, unattended excessive hoarding can create health and safety issues for patients and family members. Hoarding has been studied primarily in patients with obsessive compulsive disorder and the general population. Little research has investigated hoarding in older adults with dementia. Two published studies addressed this issue. The first was a case study examining caregiver management (Schroepfer & Ingersoll-Dayton, 2001). The second used a quantitative approach to identify the characteristics and psychiatric symptoms associated with hoarding behavior (Huang et al., 1998). The latter suggested that a better understanding of the pathogenesis of hoarding behavior might lead to better-informed treatment decisions.

Although past research into BPSD has focused on the patient’s perspective, family members can be representative of the patient because family members are most familiar with the patient’s past and current situation and are often the most capable of providing accurate information in light of patient cognitive impairment, communication difficulties, and inaccurate memories of past events. This study thus aimed to explore the characteristics and underlying meaning of hoarding behavior in elders with Alzheimer’s dementia from the perspective of family caregivers.

**Methods**

**Participants**

We conducted an exploratory research design with qualitative data collection. Purposeful sampling was utilized. Eighteen family caregivers were referred for the study by an outpatient dementia clinic (nine caregivers) and local dementia association (nine caregivers). Inclusion criteria required that caregivers were relatives of their care recipients, were at least 20 years of age, had cared for their relative for at least 6 months, and were knowledgeable about the patient’s life experiences. Patient inclusion criteria were as follows: having Alzheimer’s type dementia through physician’s diagnosis, at least 65 years of age, and currently exhibiting hoarding behavior. A total of 12 family caregivers met the criteria and agreed to participate in one-on-one in-depth interviews. All enrolled caregivers were women between the ages of 47 and 78 years; seven had completed high school only, and five were college graduates. Length of provided care ranged from 6 months to 20 years; seven participants were daughters, four were daughters-in-law, and one was a spouse.

**Procedures**

The authors obtained approval for this study from the university hospital’s institutional review board on human protection. Objectives, risks, and the potential benefits of participating in the study were explained, and written consent was obtained from each participant before the interview. Patient anonymity was preserved. An interview guide was developed by an expert panel comprising two professors with qualitative research expertise in nursing and social science, respectively, and two clinicians with expertise in nursing and geriatrics, respectively. The interview guide asked the participant the following:

1. Please describe in detail the specific hoarding behavior your relative demonstrates.
2. Under what circumstances does your relative’s hoarding behavior appear to become more severe?
3. Please share with me what you know about your relative’s life experiences.
4. What do you think your relative is trying to communicate or express when she/he has hoarding behavior?

One female researcher with a background in geriatrics and dementia conducted the interviews. Interviews took place at the participants’ convenience and were tape-recorded. All tape-recorded interviews were transcribed within 2 days. Recruitment efforts and interviews ceased when it appeared data had reached theoretical saturation. Data analysis commenced during data collection.

**Data Analysis and Rigor**

The directed content analysis approach described by Hsieh and Shannon (2005) for data analysis, which argues that an existing theory can help focus the research question, was used. Need-driven dementia-compromised behaviors served as an initial framework to identify background and proximal factors of the hoarding behavior of the patient with Alzheimer’s dementia. Methods used to code and categorize data were adapted from the three coding levels discussed by Graneheim and Lundman (2004). The researcher read all transcripts line by line and paragraph by paragraph and highlighted all text that appeared to represent components and the underlying meaning of hoarding behavior. All highlighted passages were coded, and codes were then compared and sorted into concepts. Finally, concepts were formulated into categories, and subconcepts...
were described. To ensure trustworthiness, two qualitative research experts read selected transcripts and mutually agreed upon the codes and concepts. Peer debriefing was also conducted with a focus group of six participants.

**Results**

The family participants’ ages are between 47 and 78 years and are all women; five of them completed college education, and the rest received high school education; the length of caregiving was from 6 months to 20 years; seven are daughters, four are daughters-in-law, and one is a wife. The care recipients (patients) are mostly women; only four are men. Their ages are between 74 and 92 years; five are illiterate. Most of them are widowed or married and are in the moderate stage of dementia. Participants reported food, money, checkbooks, important objects such as property certificates and keys, and useful objects (e.g., masks, spoons) as the items care recipients hoarded most frequently.

**Characteristics Related to Hoarding Behavior**

Three main characteristics related to Alzheimer’s dementia hoarding behavior emerged from the data were as follows: (1) influence of former and current symptoms, (2) recurrence of the original personal characteristics and habits, and (3) re-experiencing past economic crises. Each concept is discussed, and examples provided below.

**Influence of former and current symptoms**

Influence of former and current symptoms refers to that previous hoarding behavior and current memory impairment and delusion have effects on hoarding, which makes the hoarding behavior to become more severe. Together, these symptoms create a vicious cycle in which a patient believes that a personal article he or she previously hid and later forgot was stolen. The belief that hidden but forgotten items were stolen caused the hoarding behavior to escalate. The cycle is as follows: hiding the item then losing it, forgetfulness and delusional thoughts (believing the item was stolen), and resultant hoarding. Subconcepts identified in this category included exacerbations of inherent behavior, forgetting item locations, and delusions about items being stolen.

**Exacerbations of inherent behavior.** Patients who had previously shown hoarding behavior when they were younger and not demented tended to demonstrate more severe behavior as their disease progressed. For example, patients who hid only money before or during the early stage of their disease tended to hoard keys and medicines as their disease became more severe. They also tended to choose inappropriate places such as the refrigerator to hide such items. Although some patients originally did not hoard before the diagnosis of the disease, hoarding behavior developed and became more severe as their disease progressed.

**Recurrence of the original personal characteristics and habits**

Recurrence of characteristics and habits refers to the reappearance of the original personal characteristics and habits...
Participants described their I really think she is extremely insecure Shortages of money, food, Her family was poor when she was Family members reported care She never misplaced her bankbook or ATM cards before. Now she wraps them up in an envelope or in a medicine bag.... She is cautious because she is afraid they’ll get lost or her identity will be known by others. Her brain is in continuous caution mode.

Re-experiencing past economic crises Study participants were caring for elders between 74 and 92 years old, which meant many had lived through the Great Depression. They placed a high value on money and saved money for the “rainy day” to promote a sense of security. In the present, they hoarded readily available materials as a consequence of past economic insecurity. Subconcepts identified in this category included past resource deficiencies and uncertainties about household finances.

Past resource deficiencies. Shortages of money, food, and daily necessities in the past encouraged care recipients in their youth to save surpluses for contingencies. Even though their later years were spent in relative prosperity, they retained the residual impressions of their early experiences. They wanted to hoard items to maintain control over their material lives.

Case G: She never misplaced her bankbook or ATM cards before. Now she wraps them up in an envelope or in a medicine bag.... She is cautious because she is afraid they’ll get lost or her identity will be known by others. Her brain is in continuous caution mode.

Case C: They were poor when she married into this family.... I heard they had to hand over their salary to their parents, so she had no money herself. She wanted to have her own money to use for when the children needed to buy something or see a doctor....

Case I: She picks up whatever she sees on the table. Pick up rocks! At home too, she grabs whatever is on the table and hides it in her pocket... she says she will need it one day.

Uncertainties about household finances. In addition to national economic difficulties, we found past problems with household finances to be strongly associated with patient hoarding behavior. Impressions of financial uncertainty and insecurity exist in patients’ minds. Unfortunately, past experiences made them want to control the details of their lives as much as possible. They hoarded in an effort to maintain security.

Case C: My husband remembered that sometimes his father (patient’s husband) stayed outside gambling all night, ah... because she (the patient) was afraid that my husband’s father may run out of family money... well, he really lost a lot of money in gambling, so she saved whenever she got money to keep her family safe.

Case B: I really think she is extremely insecure because years ago... my husband’s younger brother used the house as loan collateral... when my

when he or she became ill. Interviews revealed that patients with hoarding behavior shared common personality traits, namely frugality and prudence. Almost all patients with Alzheimer’s dementia with hoarding behavior in this study had lived frugally in the past and carefully managed money-related issues. They also had cautious personalities. Hoarding behavior may be a manifestation of these personality traits. Personal habits can also be developed through life experiences and the social-cultural environment. Previous habits and current hoarding behavior shared a considerable degree of similarity, with the difference that hoarding behavior worsens as the disease progresses. Subconcepts identified in this category included retaining past frugality and prior cautious attitude.

Renating past frugality. Participants described their wards as frugal, possibly due to poor living circumstances in the past. Most care recipients in this study were dependent women who did not have an income of their own. The women traditionally needed to manage family financial issues and thus adopted a frugal personality. Although systematic and purposeful collection of daily living necessities was a common habit before the disease, its frequency and inappropriateness after onset made it more than caregivers could tolerate.

Case H: Her family was poor when she was young, had many siblings, so got to be very frugal.... I really feel that this has something to do with her childhood habits.... On one occasion, I saw her picking up many discarded pencils and trying to hide them. I asked her why, and she said some day other people could use them... also she collected lots of used masks and washed them... five or six masks... this is from her past habit.

Case K: He lived in the countryside, wasn’t rich, so he had to be very frugal. Before the disease when he ate a meal, he ate more rice and little of the side dish (more expensive than rice)... now he boards food....

Prior cautious attitude. Family members reported care recipients with hoarding behavior as cautious. Important personal belongings such as money, bankbooks, and personal seals had always been important to these individuals. Hoarding behavior thus reflected earlier priorities. However, the disease sometimes made it difficult for them to distinguish the value or importance of various items.

Case A: Because he has always been this way.... He used to keep his own bankbook, personal seal... and now he hides hoards them in a secret place.... Whatever item he feels is very important, he boards. He feels that he should treat the important things very carefully... he boards and boards....

Case C: They were poor when she married into this family.... I heard they had to hand over their salary to their parents, so she had no money herself. She wanted to have her own money to use for when the children needed to buy something or see a doctor....

Case I: She picks up whatever she sees on the table. Pick up rocks! At home too, she grabs whatever is on the table and hides it in her pocket... she says she will need it one day.

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Case B: I really think she is extremely insecure because years ago... my husband’s younger brother used the house as loan collateral... when my
mother-in-law (the patient) found out, she was very, very angry. Now she has this disease, it seems like she keeps thinking that some family members will take away her money and property.... She wanted me to hide the property certificate.... I feel that this behavior is connected to her past....

Underlying Meaning of Hoarding
As caregivers shared their perspective on the components, the underlying meaning of hoarding behavior began to unfold through participants’ own initiative. For example, some participants mentioned the word “secure feeling.” From the data, we also found that patients who had experienced financial shortcomings in the past exhibited the types of hoarding behavior strongly related to material goods. Therefore, hoarding behavior may have a strong connection with a desire for security.

In this study, a desire for security primarily refers to economic or material-related security. Elders do not want to lose material things and try to acquire more to promote security. Hoarding is not a matter of needing objects but fulfills unmet psychological needs. By hoarding, patients are expressing a desire for security. Hoarding brings comfort and a sense of safety. The desire for security included the two subconcepts of gaining a steady feeling of preparedness and ensuring a stable sense of personal belongings.

Gaining a steady feeling of preparedness
Older adults used hoarding to attain a feeling of preparedness. Preparedness is perceived as reducing danger. Past financial crises cultivated an attitude of treasuring resources. Through hoarding, elders were ensuring preparedness for that “rainy day.”

Case F: She thought that it was too much for her to eat up all the food, then she hid some for an emergency need, I guess!

Case G: Once I found she had collected lots of used little spoons. I asked her, “Mom, what for?” She replied, “For eating pudding!”

Ensuring a stable sense of personal belongings
Through hoarding, patients believe that personal possessions and property are safely kept within their control and that others will not see them and thus not take them away. Hoarding grants a great sense of stability.

Case F: She always thinks that maybe someone will steal a favorite thing, particularly when she thinks it is beautiful, other people will like it too, and will take it away, and she becomes agitated if she doesn’t hide it. I think she needs this secure feeling.

Case H: My in-law likes to retrieve unused materials, but she does not want to sell them when the recycling car is here, she hides them here and there.... I guess because she thinks those recycling materials belong to her and she wants to feel secure.

Discussion
Characteristics related to hoarding behavior among elders with Alzheimer’s dementia and increasing severity in that behavior are not limited to the simple interaction among disease symptoms. Moreover, hoarding behavior is also strongly influenced by a patient’s past social and family background. In particular, almost all patients had experienced economic misfortune, which promoted a frugal and cautious nature. Personal characteristics of being frugal and prudent with finances may also be related to past financial difficulties. Behavior is thus cultivated from a variety of underlying personal experiences combined with cross-interaction among symptoms relevant to the disease state.

Family caregivers directly attributed hoarding behavior to Alzheimer’s dementia. Although possibly related to the lack of knowledge of the disease pathology, the participants seldom suggested other causes for this behavior. By reminiscing about a patient’s past, many family caregivers sensed that hoarding behavior reflected prior experiences and inherent personality traits. This made caregivers more sympathetic about hoarding, hiding, and forgetfulness.

The link between past experiences and behavior is consistent with Shomaker’s (1987) conception that AD intensifies a person’s inherent behavior patterns and frequency. Therefore, disease is not the only explanation for hoarding behavior. The disease is like a magnifying glass that makes the behavior more pronounced and perceptible. The findings of the current study further clarified how disease components interplay with past experiences.

A patient’s coping methods and living patterns did not significantly change after the Alzheimer’s dementia diagnosis. Rather, behaviors increased in frequency to a level beyond what caregivers could comfortably handle. These findings support those of a similar study by Kolanowski, Strand, and Whall (1997), which found that patients tend to use techniques learned in the past to address various current situations. Patients who were inherently frugal or stingy saw these character traits amplified by dementia. Atchley (1989) used continuity theory to demonstrate that most older adults do not change their ways of thinking, activities, living arrangements, or relationships after becoming physically ill. In old age, individuals tend to follow patterns of behavior consistent with when they were younger. This affirms that personality, past experiences, and behavior share a consistent trajectory, even in persons with dementia.

Findings revealed that past financial difficulties engendered habits of taking precautions to prepare for a recurrence of events. It is understandable that any surplus is naturally saved for later use during economically insecure situations. In this study, daily necessities such as money
and food were principal targets of hoarding. Because savings help ensure stability for the future, these patients were following a well-established lifelong pattern. However, the disease caused them to forget about hidden items and did not allow them to discriminate the value of various hoarded objects. Family members expressed concern that elders would lose things of value. As a result family members would take away valuables such as money, leaving food as the only “valuable” commodity that care recipients could hoard. Our findings suggest an explanation as to why many patients with Alzheimer’s dementia hoard food.

Study findings are consistent with the background factors in the NDB model described by Algase et al. (1996). Past life experience, personality, and past life events are background factors that correlate with problem behaviors. However, we found hoarding behavior unrelated to proximal factors in the NDB model, inferring that patient hoarding behavior is not necessarily subject to current situations. Therefore, to understand patient hoarding behavior, learning about past life situations is more meaningful than seeking possible meanings in a patient's current reality.

An important finding was that hoarding behavior reflects internal patient needs and that they gain a sense of security through hoarding. This finding supports the NDB model. The patient in pursuit of a desired goal that expresses inner needs shows meaningful and purposeful communication behavior (Algase et al., 1996). Older adults still possess the ability and energy to adapt to the external environment. Although the patient’s physical function and self-care ability has declined, they obtain a sense of control and self-determination by facing up to environmental challenges.

Our findings support the need for health professionals to plan patient-centered care with family member involvement. Family members provide insight into a patient’s past life experiences. Understanding each individual patient’s past experience may assist caregivers to incorporate past trajectory experiences into current behaviors. Caregivers, for example, may choose to respect the frugal character or habit of a person with mild hoarding behavior before the onset of the disease. By understanding the underlying meaning of hoarding behavior, care providers may identify ways to better meet patient security needs. Met needs enhance self-esteem and self-identify. Finally, education can further help caregivers understand hoarding behavior and learn effective hoarding behavior management strategies. Caregivers should be taught useful skills to interact and communicate with patients with hoarding behavior. Most importantly, patient behavior should not be viewed as a problem to be eliminated. Rather, by accepting such behavior as reflecting an inner need, it is less troublesome for family members.

Limitations

Although this study focused on Alzheimer’s dementia patient hoarding behavior, data used reflected the perspective of family caregivers and, thus, may reflect subjective biases. Caution must be taken when interpreting the study findings to populations of different life background experiences.

Future Research

A similar life trajectory perspective may be applied to study other Alzheimer’s dementia-related problem behaviors such as delusions, repetitive behavior, wandering, and agitation. Comparisons of behavior patterns and characteristics may be made among different problem behavior types. Follow-up quantitative research will be necessary to make the results of this study more robust. Understanding how life experience trajectories influence other behaviors could benefit from a longitudinal cohort research approach. These life experience trajectories may provide insights into behaviors of older adults with other chronic diseases or patients with mild Alzheimer’s dementia, which may help better elicit information regarding the causes of particular behaviors. Finally, interdisciplinary research, for example, studying associations between biogenetic factors and behavior characteristics in certain behavioral problems of AD patients, could reveal other important components or factors involved in these challenging behavioral changes.

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References


從照顧者角度探討阿茲海默氏症失智老人的藏匿行為之
構成要素與背後意義

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背 景
失智症及其相關問題行為一直以來困擾著家庭照顧者與專業照顧者。探討患者干擾行為的構成要素與背後代表意義，可為提供以患者為中心照護的第一步。雖然藏匿／囤積行為看似不具立即傷害性，若忽視之，過度的藏匿／囤積對患者本身與照護者的健康與安全仍是有威脅的。

目 的
本研究的目的是從家屬照顧者的角度，探討阿茲海默型失智老人藏匿／囤積行為的構成要素與背後代表意義。

方 法
本研究採質性探索性研究設計，以立意取樣方式，深度訪談12位阿茲海默型失智老人的家庭照顧者，並以內容分析法分析資料。

結 果
資料分析出三項影響藏匿／囤積行為的構成要素概念，含過去與現在症狀的影響、內在個性習慣的再現、過去經濟危機感的重現。這些概念代表除患者目前生活情境外，其過去社會與家庭背景也強烈影響該行為。而藏匿／囤積行為的背後意義代表著患者對安全感的企求。

討 論
本研究結果可提供家庭或專業照顧者對失智相關問題行為之瞭解，提升照顧者對患者行為的瞭解能增進其彼此的互動與溝通。如此一來，照顧者較能找到滿足患者需求之門路。

關鍵詞：阿茲海默氏症、失智、藏匿／囤積行為、安全感需求。