

Self-Care in Elders with Dementia: A Concept Analysis

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Purpose: The purpose of this study was to analyze the concept of self-care in elders with dementia through a review of nursing literature and to provide more understanding of the definition and perspectives of the concept of self-care notion in elders with dementia.

Methods: The technique developed by Walker and Avant was used as a guide in analyzing the concept of self-care.

Results: Attributes of self-care in dementia may include a single or group of actions needed for sustaining life, a personal effort to maintain functional independence while minimizing other's assistance, an outcome behavior from the person's interaction with inter-personal and/or contextual environment, and a functional ability that may decline in parallel to cognitive impairment. Antecedents of self-care in dementia may include at least presence of a certain degree of cognitive appraisal for the self-care needs, self-willingness for the self-care action, spatial and visual orientation, cultural pre-conception of the self-care behavior, presence of environmental context/equipment available for self-care, and sufficient time available. The consequences may include sustaining of life, feel of satisfaction, achieving independence, extended life expectancy, increased self-confidence, decreased caregiver distress and/or burden, savings in health care costs.

Discussion: Defining attributes and antecedents and consequences of self-care in dementia identified in this study provided empirical ground of a middle-range theory of self-care for a clinical population with dementia and generated possible hypotheses to be tested in future studies.

Key Words : Self-Care, Dementia

INTRODUCTION

Self-care (SC) is one of the most widely known concepts in nursing. Conceptualized as self-protective actions to maintain one's individual well-being, SC has been extensively explored in nursing research and practice, and has been frequently cited as a basic theoretical concept in nursing literature (Jirovec & Kasno, 1993; Padula 1992). However, focusing of the concept of SC on a specific disease population has been minimally tried although SC needs and patterns may be differenti-

ated among the various illnesses. Acknowledging that the concept of SC has not been clearly defined in the literature on dementia, a concept analysis on SC in dementia was conducted. The findings of this study would provide empirical ground in developing a middle-range theory of self-care for a clinical population with dementia and generate possible hypotheses to be tested in future studies.

CONCEPT ANALYSIS METHOD

The technique developed by Walker and Avant (1995)

was used as a guide in analyzing the concept of SC in dementia. Walker and Avant's concept analysis method is an adopted Wilson-derived method involving eight steps: a) selection of a concept, b) the purpose of analysis, c) uses of the concept, d) defining attributes, e) model case, f) contrary case, g) antecedents and consequences, and h) empirical reference. The inclusion criteria of the literature were a) the literature has been published since 1990 in English, b) SC was used as either a title word or a text word, and c) SC was conceptually relevant to SC of elders with dementia. At first, an initial computerized search for the literature published from 1990 to 2003 was done using three search engines: Medline, CINAHL, and PsychInfo. A combined entry of two words, 'self-care' and 'dementia' as main subjects or key words resulted in a total of 205 citations located. Among these, 21 non-English literature and 51 overlapping literature across the search engines were excluded, resulting in 133 remaining studies. Then 77 studies were excluded as they did not meet the sample inclusion criteria. A total of 56 studies were reviewed for this analysis. Although this number is not as large as what was anticipated at the start of the literature search, all of them were selected because of the close proximity of their content to the main concept of this study. Once the final list of the literature was obtained, the relevance of each document to the main topic was evaluated by the investigator. Then, overall contents of the selected literature were analyzed using an inductive process to find the main attributes and constructs of SC in elders with demented elderly.

RESULTS

Step 1: Selection of the Concept

The concept of SC was first introduced by Virginia Henderson in the mid 1950s and further focused by Dorothea Orem in 1959 who viewed SC as the important activities of a human being to take care of oneself and described it as a salient parameter to lead to positive health outcomes of the individuals (George, 1980). As for dementia, although pathophysiological processes of dementia have been identified clearly in the past, the issue of preserving SC abilities in elders with dementia in the actual care-giving context has received insufficient attention in the nursing literature. Because the level of one's SC determine the individual's care needs, exploring the concept of SC in dementia would be critically re-

lated to nursing outcome such as cost and care-giver distress. Although fostering SC is a useful strategy for managing behavioral disturbances in patients with dementia (Forbes, 1998; Woods, 1999; Vogelpohl, Beck, Heacock, & Mercer, 1996), the actual definition and attributes of SC in dementia have been rarely examined and wide variability of the operational definition of the term has been found in the literature. This lack of consensus on the terminology and taxonomy of SC in elders with dementia provided a need for more systematic analysis of this concept in old age and a title would be to be used in the following text to be given to self-care.

Step 2: Purpose of Analysis

The primary question of this study originated from inquiry on how much is known about SC abilities of elders with dementia. This study analyzed the concept of SC in the elders with dementia through a review of literature in order to provide more understanding of the definition and characteristics of the SC in elders with dementia.

Step 3: Current Usage of the Concept

Generic Definitions

As the first step of the concept analysis, generic definitions of SC and dementia were explored. Dementia refers to a neuropsychiatric disease in which progressive impairment of cognitive function is experienced, resulting in interference with normal social and occupational activities. It is characterized by impaired memory, language, and reasoning as well as behavioral disturbances (Ayd, 2000). For the generic definition of SC, Orem's SC model (1991) has been usefully applied to older persons at home (Jopp, Carroll, & Waters, 1993) and in long-term care settings (Easton, 1993). According to Orem, SC is "an action of mature and maturing persons who have developed the capabilities to take care of themselves in their environmental situations" (Orem, 1991, p. 117). These generic definitions of both dementia and SC provide an initial point where the conjoining meaning of SC in dementia can be sought for in the literature. Because the purpose of this study is to analyze the concept of SC in dementia, the main interest in how the meaning of SC can be operationalized in the context of dementing illness and what are the antecedents and consequences of the phenomenon of SC in elders with dementia.

Self-care as Activities of Daily Living

The meaning of SC in the general population is often

extended to instrumental activities of daily living (IADL) as well as psychosocial dimensions such as managing one's finances, medication, and transportation. The review of literature showed that SC of elders with dementia mostly referred to basic activities of daily living (ADL), such as eating, toileting, bathing, and dressing, rather than as IADL. The main construct of the ADL in dementia found in the literature included these vital life-sustaining activities. This different standard of SC in dementia may be due to the fact that the observed patterns of SC in elders with dementia have been confined to essential life-sustaining activities, which mainly comes from impairment in cognition that is unavoidable with the progress of the dementia itself.

Self-Care as an Empirically Observable Behavior

A review of the current usage of the term SC in the literature showed that SC in elders with dementia referred to actual behavior rather than to the person's internal capability or verbal expression of his/her needs for the SC. For instance, an elder with dementia may be viewed as completing self-care when the person demonstrates an actual performance of self-feeding, not when the person just verbally expresses his/her capability of self-feeding or intentionally skipping the meal although he/she had the ability of self-feeding. Therefore, in evaluating SC of an elder with dementia, it is important for caregivers or nurses to make an empirical observation of the completion of self-care performed by the patient, rather than to rely on the indirect report or intuitive interpretation of the patient's capability of the behavior. That is, actual performances by the patient may be the most precise evidence of SC in elders with dementia.

Self-care as a Continuum

SC in elders with dementia elderly is also viewed as a continuum rather than a dichotomy. When addressing the impaired SC in elders with dementia, many studies have taken the severity of the impairment as their central issue rather than whether the impairment of SC occurred or not. This view of SC as a continuum is also supported by the fact that SC in elders with dementia has been found to decline in a hierarchical manner in the order of complexity from occupational task to IADL, to ADL (Green, Mohs, Schmeidler, Aryan, & Davis, 1993). These attributes of SC in elders with dementia are reflected in scales to measure SC in elders with dementia, which are mostly composed of a continuous scale, rather

than a dichotomous measurement.

Variability of Self-care within Individuals

The presence of individual variability of SC in elders with dementia was also found in the literature review. SC was generally related to the severity of dementia but also varied among individuals who are in an identical type or stage of dementia. Although there is a certain commonality in declining of SC patterns among elders with dementia, it is difficult to generalize that all elders shows an identical degree of functional independence. This highly individualized SC pattern in demented elderly has been a theoretical basis for studies in which an individualized approach was used as a strategy to enhance functional independence of elders with dementia (Vogelpohl et al., 1996).

The Impact of Environment on Self-care

SC in elders with dementia is viewed as a functional performance to which environmental factors are related. These environmental factors may include both interpersonal and contextual factors, such as caregiver attitude (Vohelpohl et al., 1996), home environment (Gitlin & Corcoran, 1996), and living arrangement (Edwards & Baum, 1996). For instance, elders with dementia living independently are more likely to have a higher level of functional ability than those living with other family members, despite similar levels of cognitive impairment. The mutual impact of interactions between the patient and caregiver on SC of the patient was also noted. It is well known that emotional and functional disturbances of a person with dementia lead to caregiver distress (Donaldson, Tarrier, & Burns, 1998; Ford, Goode, Barrett, Harrell, & Haley, 1997), but it has received less consideration in nursing literature that the caregiver's attitude and intent to foster SC in the elderly may also impact the functional outcome of elders with dementia (Vogelpohl et al., 1996). This finding implies the importance of caregivers' roles in the functional independence of SC in elders with demented elderly. It may be an issue of future inquiry how much differences in functional independence of the demented patients with identical stages of dementia may exist between those who receive the supports by caregivers with special training and those who do not.

Step 4: Defining Attributes

The analysis of the concept of SC in elders with de-

mentia based on the review of relevant literature showed the following defining attributes of SC in elders with dementia:

1. A single or group of actions needed for sustaining life (e.g., feeding, and eliminating) as well as basic daily life activities (e.g., dressing, bathing, grooming, and ambulation),
2. A personal effort to maintain functional independence while minimizing others' assistance, despite experiencing cognitive impairment from dementia,
3. An outcome behavior of the elder from the person's interaction with inter-personal and contextual environment, and
4. A functional ability that may declined in parallel to cognitive impairment, but not necessarily identical in its pattern to declining of cognition.

Step 5: Model Case

TD is a 85 year old female nursing home resident. She suffers from moderate dementia and Parkinson's disease and takes prescribed neuroleptics three times a day on a regular basis. She is wheelchair bound and incontinent, and needs two assistants when transporting and ambulating herself. Although her short-term memory and special orientation are severely impaired, she is alert and oriented to person if given sufficient time for cognitive activity and shows a strong sense of independence and will for SC. At dinner time, a nurse aid brings a meal tray and put it on the dining table in front of TD with a full cup of water. When the aid puts plastic utensils in her hand, TD starts eating by herself using her right hand, her dominant hand with less tremors, with occasional spilling of food. She slowly repeats the feeding activity under the supervision of the nursing staff and completes the meal in 50 minutes. Intermittent verbal direction and interaction are made by the staff regarding swallowing manner or balance of her choice on the menu. After completing the feeding activity, TD feels immediate sense of gastric fullness and self-confidence. By repeating this pattern, TD would continue to sustain her life with optimal energy level while minimizing other's assistance, and may preserve higher level of SC on eating function compared to others in a same stage of dementia who depend entirely on the nursing staff regarding feeding activity.

Step 6: Contrary Case

BC is a 77 year old woman living at home who is re-

cently widowed. She was previously diagnosed with mild dementia and is currently taking neuroleptics as well as stool softeners and anti-hypertensives. She is living with an unmarried daughter and mostly staying at home alone while her daughter is at work. She usually has a ready prepared lunch in the refrigerator which she warms in a microwave. However, she has a strong perception of having lunch as a family event and has little will to eat alone. She knows the location of utensils and foods but perceives that the kitchen table is still too high for her height. There was also no correspondence or interaction with family, which reminds her of her meal time. As the result, although a certain degree of hunger exists, she does not walk to the kitchen and set up a meal tray for her, and does not initiate the feeding activity. By skipping a meal, BC experiences gastric discomfort and low energy level for the day as well as a decline in bowel movement on the day. By repeating this low level of SC, BC would lose body weight and experience decreased life satisfaction in a long-term. BC would also have less functional ability compared to others in a same stage of dementia and raise more care-giver distress.

Step 7: Antecedents and Consequences

A set of antecedents and consequences were identified through the review of the literature. The components of antecedents and consequences are presented as the conceptual frame in Figure 1.

Antecedents

A set of antecedents that should occur prior to the SC has been identified.

The SC in elders with dementia may occur only when the person has: at least presence of a certain degree of cognitive appraisal for SC needs, self-willingness for SC, spatial and visual orientation, cultural pre-conception of SC, presence of environmental context/equipment available for SC, and sufficient time available. These antecedent conditions should be met before the occurrence of a SC in an elder with dementia.

Consequences

The consequences may include sustaining of life, feel of satisfaction, achieving independence, extended life expectancy, increased self-confidence, decreased caregiver distress and/or burden, savings in health care costs. All these consequences are beneficial results of SC in elders with dementia.

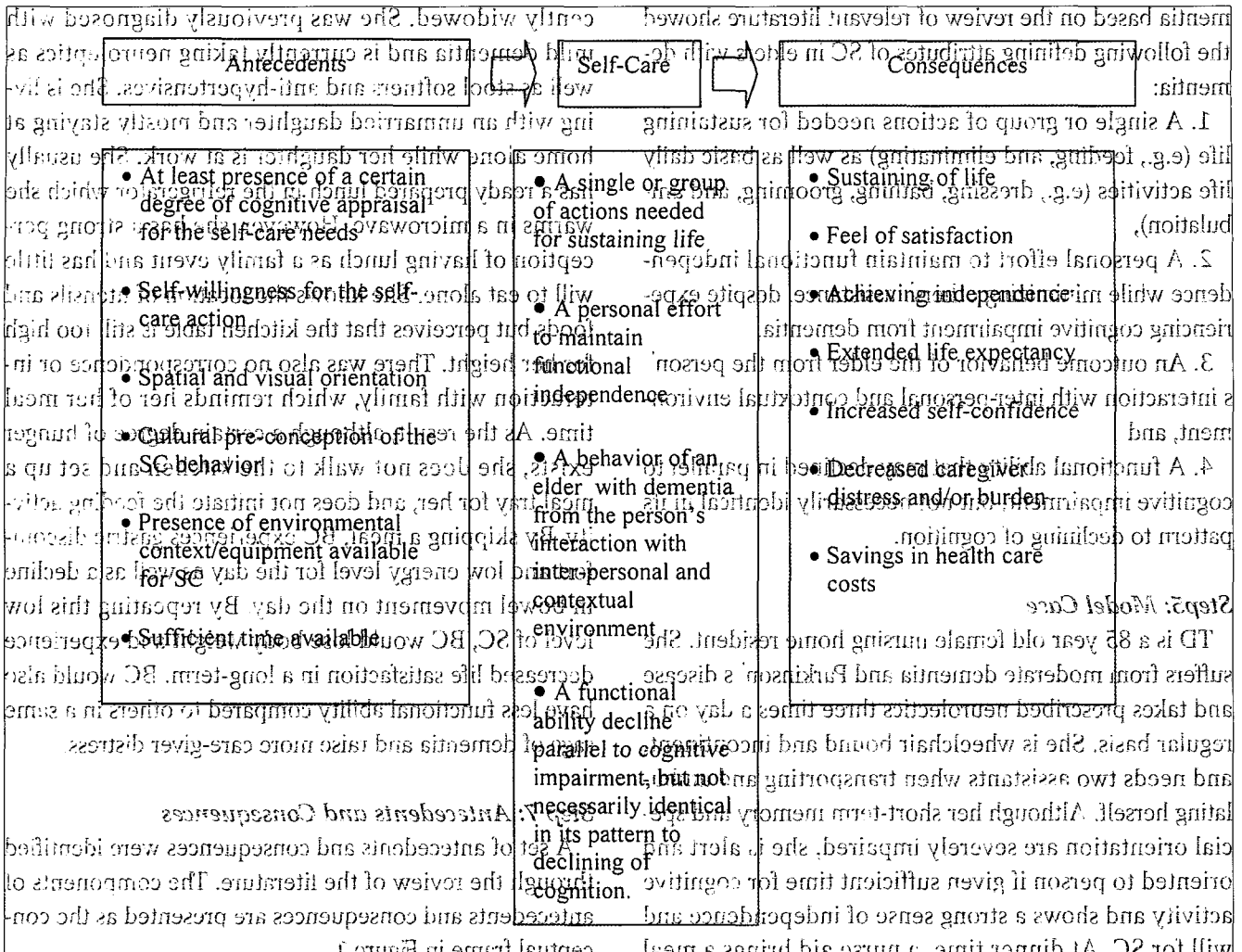


Figure 1. Antecedents and consequences of self-care in dementia

Table 1. Empirical References of Self-care for a Clinical Population of Dementia

Types	Instruments	Developers
Informant-based scale	Blessed Dementia Scale Cleveland ADL Scale OARS-ADL	Blessed, Tomlinson, and Roth (1968) Patterson et al. (1992) Duke University Center for the Study on Aging (1978)
	Functional Assessment Staging Scale (FAST) Changes in Advanced Dementia Scale	Reisberg (1988) McCracken, Glister, Connerston, Canfield, and Painter-Romanello (1993)
Performance-based scale	Structured Assessment of Independent Living Index Direct Assessment of Functional Status Refined ADL Assessment ADL Situation Test	Mahurin, DeBettignies, and Pinizzolo (1991) Loewenstein et al. (1989) Tappen (1994) Skurla, Rogers, and Sunderland (1988)
	The Abilities Assessment Instrument (AAI) Performed Test of Activities of Daily Living Disability Assessment for Dementia (DAD)	Dawson, Wells, Reid, and Sidani (1998) Kuranusky & Garland (1976) Gelinas, Gauthier, McIntyre, and Gauthier (1999)
	Cognitive Performance Test	Burns, Mortimer, and Merchak (1994)

Step 8: Empirical References

Empirical references of SC in elders with dementia found in the literature were mostly evidenced in the form of instruments to measure the concept. These instruments were usable to measure the concept of SC in elders with dementia and were classified into two types, informant-based scales and performance-based scales (Table 1).

DISCUSSION

The concept analysis conducted in this study showed the defining attributes as well as antecedents and consequences of SC in elders with dementia. SC in the elders was defined as the person's single or group of actions needed for sustaining life and basic daily living in the context of declining cognition. It is an outcome behavior of the elder's interaction with the environment and refers to personal efforts to maintain functional independence while minimizing others' assistance. In order to achieve a SC, an elder should have at least a certain degree of cognitive appraisal for the SC needs and will to do it based on the person's cultural pre-conception of the behavior as well as spatial and visual orientation and sufficient time to conduct it. As the results of the SC, the person may sustain life, have the feeling of satisfaction and independence, and decrease caregiver distress and health care costs related to the SC.

One limitation in preserving the SC abilities of elders with dementia is the essential dependency on cognitive ability that is often irreversibly diminished. Because a certain degree of cognitive appraisal of the SC needs is a vital component of the antecedents, progressive impairment in cognition may bring a fundamental defect for performing a SC. Therefore, it should be noted that preserving the maximum functional independence in the elder may only be somewhat successful as long as the cognitive impairment has progressed in the course of the disease. Nevertheless, the extent to which nurses can contribute to achieving optimal functional independence is still under exploration and should be further studied.

Empirical reference is another issue to be discussed. Although a number of generic scales have been developed to measure the concept of SC, only a few dementia-specific scales have been found in the literature. In addition, it was noted that most instruments have been used for several studies mostly conducted by the original developers and there has been little consensus regarding

a gold standard of the tool to measure SC of elders with dementia that has been widely replicated in studies. Therefore, the reliability and validity of the dementia-specific scales may need to be further evaluated as well as the applicability of the generic scales to populations with dementia.

This study poses several implications from the perspectives of both clinical practice and research. From the perspective of clinical practice, first and foremost, nurses should be aware that their expectations for SC in elders with dementia may need to be adjusted to a level that is primarily focused on the normal life-sustaining activities such as eating, toileting, bathing, and dressing. It is also important for nurses to appraise individual variability of SC among elders with dementia. Although the potential capability of SC should be appraised, the confirmative evaluation of SC should be based on the empirical demonstration of SC performed by the elder. In addition, clinicians also have to give attention to the fact that caregiver attitude may impact the level of SC of elders with dementia.

From the perspective of research, findings of this study may be integrated into current grand nursing theories of SC. Taking Orem's model (1991) as a grand theory, a middle range theory on SC specifically for a clinical population with dementia may be designed based on the findings of this study. For instance, possible hypotheses related to impact of each antecedent on SC for elders with dementia may be tested in future studies using the operational definition identified of this study. It is also of interest to examine the relationships among the factors relevant to the notion of SC in elders with dementia. Further concept synthesis and classification process is also needed in order to develop a more concise mid-range theory that can explain the clear feature of SC in elders with dementia.

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