Intergenerational caregiving: adult caregivers and their aging parents

Theory-generating methodologies can be used to add to our knowledge in areas that are already well researched in addition to areas that have not been extensively studied. The study presented here demonstrates how the grounded-theory method was used to generate a new theory of intergenerational caregiving. Analysis revealed five conceptually distinct, overlapping categories of caregiving. Only one of these includes what is generally considered to be caregiving, that is, hands-on caregiving behaviors or tasks. The other four types are not observable behaviors but are processes crucial to intergenerational caregiving and to an understanding of the experience of intergenerational caregiving.

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NTERGENERATIONAL caregiving is L becoming a significant issue for nurses practicing in a variety of settings. Nurses are in a pivotal position to provide care to both aged individuals and their family caregivers. The findings from the study presented in this article indicate that nurses and other health care professionals may lack an adequate understanding of family caregiving experience, precluding effective nursing intervention. What many family caregivers consider their most important work (protection) is often not considered at all by health care professionals. Despite the volumes of caregiving research, a theory-generating method of analysis, grounded in caregiver experience, can provide useful new insights having both practical and theoretical implications.

BACKGROUND

During the past decade, family caregiving research has experienced an explosive

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growth resulting in a large and diverse knowledge base. The variables investigated, the hypotheses generated, and the questions asked by researchers cover a wide range of topics but can be conceptually divided into the following general categories: (1) characteristics of those in need of care; (2) characteristics of caregivers; (3) content of caregiving; (4) impact of caregiving on the frail, elderly population; and (5) impact of caregiving on caregivers.

Based on recent US Bureau of the Census data, both the number and proportion of individuals over 65 continue to grow. In 1900, only 4% of Americans were over 65 as compared with the current 11.3%. Projections indicate continued growth of this age group to 21.8% by 2050.1 Even more striking is the growth in the very old population. The over-85 group is expected to triple between 1980 and 2020. The significance of these data is underscored by a national study of well-being in the elderly, which reported the tremendous rise in general impairment levels corresponding to increases in age.2 According to this report, only 6.3% of the US population under 70 is extremely impaired, while 9.3% of those between 75 and 79 and 22.5% of those over 85 are classified as extremely impaired. Many of these extremely impaired elderly can be found among the institutionalized populations. However, many more remain in their own homes with assistance from caring relatives.

Townsend's³ recent study in Britain indicates that there are three times as many severely impaired individuals living at home than in all institutional settings combined. These data supported the findings of several other investigators, which repeatedly demonstrate the significance of

family caregiving in preventing institutionalization of the elderly. Accent government policies have increasingly been targeted at supporting or mandating family caregiving in an attempt to reduce institutionalization. While not all of these noninstitutionalized, impaired elderly have relatives to care for them at home, there is a strong positive correlation between increasing age and likelihood of moving into the home of relatives. 49

Research on family caregiving has demonstrated the predominance of women, particularly wives and daughters, among the care providers for our nation's elderly.6,9,10 These female caregivers tend, increasingly, to be participants in the paid labor force outside the home as well as being unpaid care providers within the home. 11-14 A number of recent studies 12,15,16 have documented the burden placed on these women caregivers and the stress experienced by them. Brody's well-known discussion of "women in the middle" identified the impact of simultaneously caring for one's children and one's parents or parent. 10 Other investigations have revealed increased incidences of both psychological and somatic symptoms among groups of caregivers.

The content of family caregiving has also received considerable attention. Studies of what caregivers do generally focus on the specific tasks involved in providing care and are often defined in terms of tasks such as bathing, transporting, grooming, preparing meals, giving financial assistance, etc, often referred to as activities of daily living. Caregiving can then be evaluated in relation to which tasks are being performed by whom, how often, and with what consequences for both the elderly

and their caregiving relatives.^{3,17-20} A comprehensive review of caregiving literature by Clark and Rakowski²¹ divides caregiving into 45 separate caregiving tasks.

Overall, research on family caregiving supports or assumes a positive correlation between increasing frailty or impairment of the aged relative and caregiver stress. The assumptions are frequently made that living together is necessary for caregiving to occur and that the amount of caregiver work and stress is generally associated with performing caregiving tasks for very impaired elderly. The stress experienced by offspring of mildly impaired elderly can be easily overlooked. These caregivers are not considered at high risk and are therefore rarely included in caregiving studies. Indeed, many of these caregivers have become invisible. In order to understand this invisible caregiving and the associated stress, it is necessary to understand the world of caregiving from the perspective of the caregivers. Focusing on the tasks of caregiving effectively diverts attention from much of the work these caregivers are engaged in and renders them invisible.

STUDY OVERVIEW

Given the comprehensiveness of the caregiving literature, it seems there may be little to gain from an exploratory study. However, the current study demonstrates how a theory-generating method can add to our knowledge of an area that has already received much careful, scholarly attention. Grounding a study in the experiential world of the subjects can indicate where researchers have incorporated assumptions that are inconsistent with that world and, consequently, how those theo-

ries need to be altered. The study described here of middle-aged women caring for their aging parent(s) indicated that task-based categories are conceptually inade-quate for understanding intergenerational caregiving (IGC). The study demonstrated how a reconceptualization of caregiving activities—distinguished by purpose rather than by task—is a more accurate representation of the experience, work, and stress of IGC. It also demonstrated how a task-based focus obscured an important aspect of family caregiving work.

The findings reported here represent one piece of a much larger study looking at

The study demonstrated how a reconceptualization of caregiving activities—distinguished by purpose rather than by task—is a more accurate representation of the experience, work, and stress of an intergenerational caregiver.

intergenerational caregiving. This article focuses on the caregivers' perspectives rather than those of siblings, parents, or health care providers, all of whom are significant and will be discussed in future articles.

STUDY METHODS

A grounded dimensional analysis (a form of grounded theory) was used to conduct the study.²²⁻²⁴ The method is grounded in a phenomenological epistemology and represents what Allen²⁵ described as interpretive science. The method evolved within the sociological

tradition of symbolic interaction and is directed at developing a greater understanding of the experiential world of the research subject. Data collection and analysis are conducted concurrently, facilitating the discovery process by allowing research questions and hypotheses to evolve in response to the emerging theory. Consequently, the nature and focus of the initial research questions or hypotheses are often transformed during the research process, moving from very general to very focused.

A dimensional analysis was used to identify significant aspects of the caregiving experience. The constant-comparative, grounded-theory method was used to develop a sample of subjects and conditions representing various theoretical possibilities. Sixty interviews were conducted with 27 parents and 33 of their offspring. In some cases, the siblings of primary caregivers were also interviewed.

Caregivers range in age from 38 to 72. Thirty-one offspring caregivers were female and two were male; 18 caregivers were employed full time, 2 were employed part time, and 13 were unemployed. A caregiver employment level of 65% is consistent with the findings of previous studies. Parents ranged in age from 62 to 97. One parent was below 70, 13 parents were between 70 and 79, and 11 parents were between 80 and 86. Only two parents were over 90. This sample, therefore, represents primarily elderly in the middle range rather than the very old group.

Living arrangements varied within the sample. Unlike some caregiving studies that include only families where the older parent lives with the offspring, several parents lived alone. Only 8 parents lived

with caregiving offspring, 16 lived alone, and 3 lived in retirement centers.

THEORETICAL SAMPLING

Theoretical sampling was based on comparisons between cognitive and physical impairments and among levels of cognitive impairment. Analysis presented is based primarily on the sample of cognitively impaired. Theoretical sampling was also directed by a comparison of various living arrangements. Pairs of parents and offspring living together were compared with those living in separate residences. This sampling facilitated a focus on the invisible caregiving in which tasks were not of central importance and caregiving occurred from a distance.

DATA COLLECTION AND ANALYSIS

Data were collected through interviews that were taped, transcribed, and coded by the principal investigator. Interviews lasted from 20 minutes to three hours. Length of interviews varied in response to subjects' time restrictions and fatigue. Each subject was interviewed only once. Most interviews were conducted in the homes of the subjects, and caregivers and their parents were interviewed separately. Interview questions evolved during the study in response to the emerging theoretical categories, and the need to identify comparative conditions became more focused as the study proceeded. Some of the early research questions included:

- How does one become a caregiver?
- What is most stressful about being a caregiver?

 What is it like to be a caregiver of one's parent?

Later questions focused more on the consequences of failed caregiving and strategies for invisible caregiving. Later questions included:

- How does one care for an aging parent while preventing the parent from discovering that he or she is being cared for?
- How does this goal influence interactions with other offspring, other relatives, or health care providers?
- What strategies are used to respond to the parent who perceives that he or she is being cared for?
- Under what conditions are parents not upset about being cared for by offspring? How would this affect strategies for caregiving?

Analysis of the data from the early interviews offered insight into the research questions listed above and raised many new ones. Although it was not one of the initial research issues, the task-based definition of caregiving became problematic since it was clearly inconsistent with the caregivers' experiences. Analysis of these interviews revealed that the process of caregiving is much more complex than these commonly used definitions would indicate and that much of the stress associated with caregiving is unrelated to the performance of tasks. Furthermore, distinguishing among tasks and the time spent engaged in tasks may be irrelevant to understanding the experience of IGC.

DEFINING CAREGIVING

The work of caring for an aging parent, particularly in the presence of a mild cog-

nitive defect, was discovered to be largely invisible. This invisible work is directed primarily at protecting both the parent's self-image and established parent-off-spring relationships. Protective caregiving is experienced by many family caregivers as their most important work.

Caregiving is defined here by the meaning or purpose a caregiver attributes to a behavior rather than by the nature or demands of the behavior itself. Any process engaged in for the purpose of caregiving is therefore included. This method of defining caregiving has important implications.

First, both observable behaviors and mental activities are included. Plans and decisions made by caregivers are not observable tasks but may have important consequences for their lives. Second, consensus and shared understandings by parents and caregivers about the meaning of an activity are not necessary for an activity to be defined as caregiving. There are numerous instances in which a particular activity is perceived by one individual as caregiving, while others define the same activity quite differently. For example, caregivers were more likely than were parents to describe an activity as caregiving. Siblings of caregivers were also less likely than caregivers to perceive an activity as caregiving. Third, a behavior may serve more than one purpose simultaneously. When forced to label a particular behavior as either caregiving or something else, caregivers made purely arbitrary distinctions. Preparing a meal may be either a gesture of caring, a technical task, or both at once. A single activity such as meal preparation may be used to communicate very different messages. Frequently, the

message intended by the caregiver is not the message received by the parent or others. Because caregiving is an interpretation of a situation rather than an observable event, any situation is open to multiple and conflicting understandings.

FIVE CATEGORIES OF CAREGIVING

A dimensional analysis of the data revealed five conceptually distinct but empirically overlapping categories of family caregiving. These categories include anticipatory, preventive, supervisory, instrumental, and protective care. Only the instrumental care includes the traditional definition of caregiving, that is, the handson caregiving behavior or tasks referred to earlier. The other four types, while not defined by or directly associated with observable behaviors such as tasks, are processes crucial to the IGC experience and to our understanding of how families care for their elderly relatives.

Analysis of the first three interviews revealed all five theoretical categories of caregiving. The 57 subsequent interviews provided considerable depth and elaboration while confirming the validity and consistency of these same five categories. Protective caregiving was experienced by these caregivers as both their most significant work and the most frequent and powerful source of stress. The centrality and invisibility of protective caregiving was repeatedly confirmed by the caregivers' experiences. Although protective caregiving was central for many caring offspring, it was a particularly critical issue when the aged parent had a mild to moderate cognitive impairment. Protective caregiving actually became less of an issue as a parent's cognitive impairment became more severe.

The following briefly outlines the five types of caregiving engaged in and then focuses on the most central category of protective caregiving.

Anticipatory caregiving

Anticipatory caregiving includes behaviors or decisions that are based on anticipated, possible needs of a parent. It was usually observed in parent-offspring pairs who were not living together. It is a form of caregiving that often occurs from a distance. For example, as one woman explained:

A lot of what I decide to do myself during the next few years ... I base not only on Joe, ... my son, ... but on my parents. Right now if I wanted to find a decent job, I could find it if I moved away from San Jose. But at this point, I feel that I have a certain responsibility to be here ... just in case.

"Just in case" is the key conceptual distinction of this category. This woman's decision about which city to live in is clearly, at least in part, a caregiving decision. Anticipatory caregiving is a mental event or perception that has, in situations such as this, a powerful impact on a caregiver's actions. This form of caregiving encompasses a great range of possible behaviors. Many important life decisions involve this type of anticipatory caregiving. This category cannot be defined by any associated, observable behaviors that allow it to be identified as caregiving. It is also rarely talked about openly between parents and their offspring. Many caregivers perceive an open discussion about this antici-

patory care as threatening or insulting to their parent(s). It is a form of caregiving that is intentionally invisible. Shared understandings about the meanings of anticipatory caregiving behaviors are carefully avoided by offspring.

Preventive caregiving

Preventive caregiving frequently includes activities carried out by offspring for the purpose of preventing illness, injury, complications, and physical and mental deterioration. It generally involves more active monitoring and supervising than anticipatory caregiving. Prevention includes activities such as altering the physical environment to increase safety; questioning the parent about symptoms, medications, etc; and preparing chicken soup or meals. Again, it is distinguished by its purpose rather than its associated tasks.

Supervisory caregiving

Supervisory caregiving, the third category, is observed in situations where identifiable care is given to a parent. This type is generally experienced as an active and direct involvement of the offspring and is likely to be recognized by the parent and others as actual caregiving activity. Activities include arranging for, checking up, making sure, setting up, and checking out. They may be done with or without the parent's awareness. Archbold also identified a similar category of care, distinguishing between family care providers and care managers. Again, it is the purpose that defines the category of caregiving.

Instrumental caregiving

Instrumental caregiving includes "doing for," "assisting," "providing," and "giv-

ing." It is the hands-on caregiving more commonly recognized as caregiving. The purpose of this care is to maintain the parent's physical integrity and health status. Not surprisingly, it was most often observed in situations where the parent was ill or disabled. While this is the type of caregiving that is most often studied by social scientists, health care professionals, public health professionals, and public policy analysts, it was considered by family caregivers as the *least* important type. This perception of lesser importance is directly related to its purpose. Instrumental care is related to physical well-being and the care of the body rather than to emotional well-being and protection of the parents' identity, which are characteristic of protective care.

Protective caregiving

Protective caregiving, the fifth category, was experienced by most caregivers as the most difficult and important type of care provided. The purpose of protective caregiving is to protect the parent from the consequences of that which was not or could not be prevented. These potential consequences were perceived by caregivers as threats to the parent's self-image rather than to their physical well-being. For example, while cognitive decline could not be prevented, the parent's altered selfimage or depression resulting from the awareness of cognitive decline could be. At least caregivers believed they could affect the situation and made active attempts to do so.

A 57-year-old woman, Anne, described how her elderly mother took great pride in having dinner prepared for her each night when Anne came home from work. The mother's ability to cook was seriously affected by her mild cognitive as well as sensory impairment. This meant that Anne was frequently given meals she described as inedible (for example, salt was substituted for sugar). Rather than confront her mother with the situation, she ate what was put in front of her.

This example of protective caregiving clearly has consequences for both the parent and the caregiver. The parent's self-perception as competent and independent is protected while the daughter suffers silently over a barely edible meal. This daughter had also stopped inviting guests to dinner, fearing what her mother might serve them.

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attempts to protect the parent from awareness that she or he is being taken care of. While caregivers often used the language of role reversal, they also described their enormous efforts to prevent the parent from sharing this reversed role perception. Caregivers described the importance of protecting both the parent's identity and the parent-child relationship. An inordinate amount of protective caregiving work is directed toward this goal and creates much caregiver stress. This protective care was engaged in most intensely when a parent had a moderate cognitive impairment. Even the minimal loss of cognitive

abilities was perceived by caregivers as very threatening to a parent's self-image and to the parent-child relationship. This perceived threat accounts for much of the stress related to mild cognitive decline and the intensity of caregiving work in response to an apparently minor problem. Many caregivers were extremely successful at providing care in a way that was not perceived by the parent as caregiving, as in the following example:

A 62-year-old daughter who was caring for her frail, 92-year-old mother discussed her mother's increasing forgetfulness and confusion. The daughter was concerned because her mother's weekly trip to the bank involved three bus transfers. The daughter was fearful that the older woman might become lost in the large inner city during one of her trips. The younger woman convinced her elderly mother that their bank was unsafe. It had been robbed recently. Both women changed all of their accounts to another bank, which, coincidentally, was only a few blocks from their home.

Several offspring described what they did for a parent and the nature of their relationship with the parent as representing a reversal of roles. They described themselves as giving care to a parent who was "like their child." However, on closer observation, several discrepancies with the role reversal model were discovered. This role reversal was, in fact, very different from a simple reversing of activities and methods of interacting. The offspring had not become "like a parent," nor was the parent treated "like a child." Two important characteristics of the situation distinguished it from a simple reversal of roles. First, the parents were not aware of the offspring's perception that roles were reversed. Thus, while the offspring might see themselves as acting like a parent, the

parent never described himself or herself as feeling like a child. Preventing the parent from "discovering" a reversal of roles was an active strategy engaged in by offspring caregivers.

The second distinction is related to the first. Although what an offspring did may have been experienced as representing a role reversal, the way in which it was done was not representative of this reversal. In fact, caregivers carefully orchestrated their caregiving activities to appear as if the parent-child relationship was intact. For example, a son or daughter might claim to take care of a parent's needs, "look after" him or her, monitor health problems, etc, just as one would do for a child; however, the way in which these things were done maintained consistency of the actual parent-child relationship. Parents were checked up on or looked after in a way that was not "parental," as in the following example:

One daughter described how she telephoned her mother's physician before and after each of her mother's clinic visits. Each time, the daughter instructed the physician to write out the mother's prescriptions and treatments on a piece of paper. The daughter also requested that information be sent to the daughter so that she could supervise her mother's care at home. Finally the daughter requested that the physician not inform the mother of the conversation between physician and daughter. This revelation, the daughter believed, would be "insulting" or "demeaning" to her mother. In this way, the daughter explained, she could supervise her mother's activity while not revealing her action to her mother. As the daughter explained, "I can suggest instead of tell her. I can't tell her what to do. She's my mother. I can suggest it."

STRATEGIES FOR PROTECTIVE CAREGIVING

Caregivers engage in three strategies of protective care. The first is to protect the parent from awareness of an *event*. The example of the salty, inedible meals represents this first strategy. The daughter's silent acceptance of an offensive meal is an instance of protective caregiving. She is protecting her mother from evidence concerning the mother's competence. Although there is no observable caregiving task, the daughter's decision has clear implications for the daughter's life and should be considered an example of protective caregiving.

A second strategy is to protect the parent from awareness of the meaning of a situation. This process involves acknowledging the existence of an event while reconstructing its meaning or significance. Caregivers engaged in this second strategy when the parent could not be protected from awareness of the event. An event may be acknowledged as an isolated incident, ignoring its significance as part of a larger pattern. This is done in situations where it is the pattern or consistency of an event, rather than its substance alone, that imputes the undesired meaning. Thus, forgetting is not in itself significant; however, continual forgetting has important negative implications (ie, senility). Forgetting a pan of vegetables cooking on the stove and starting a fire and forgetting whether one has eaten breakfast have greater significance than other types of patterns of forgetting.

One daughter explained how she was never upset by her father's forgetting dates, names,

or appointments; however, she became concerned when he began to forget whether he had eaten meals. This particular forgetting was different both in its meaning and its consequences. The meaning was suddenly perceived as more serious.

Another interesting aspect of this type of protective caregiving is that siblings often disagreed about what represented "significant forgetting."

Caregivers actively reconstruct the meaning of an event or situation by rendering the event consistent with the parent's personality. Likening a developing problem to an idiosyncratic characteristic effectively neutralizes a significant event. For example, losing things may be considered an indicator of senility to the offspring but may be represented to the parent as "the way you've always been." Much of the stress associated with caregiving is related to the process of continually constructing and reconstructing the meanings of events. The sources of stress are both the amount of work related to this process and the caregivers' sense of how vulnerable this process is to the influence of outsiders.

These processes are generally used in the order in which they are listed above. Caregivers often attempt first to prevent parent awareness of an event. When this fails, strategies are aimed at careful reconstruction or control of the meaning of the event in question. Failure to control this awareness is often perceived by caregivers as having great consequences for both themselves and the parent.

One daughter described how she protects her mother from awareness of things the mother does. For example, when the mother threw out seven years of the daughter's income taxes, the

daughter did not tell her mother what she had done. This daughter also did not tell her mother about how bad the mother's cooking had become because she frequently became confused and forgot ingredients. The mother was prevented from being aware that she was doing these things. When the daughter could not prevent the mother's awareness of forgetting, misplacing, etc, the daughter redefined the situation to render the meaning of the incident not threatening to the self-characterization. For example, when the mother misplaced some important papers and left part of their dinner in the oven, the daughter joked that "you've never been able to remember those things." The daughter explained, "It's lifelong (the forgetting), so therefore, it's just a continuation, only more so. She used to put things away and one of us kids would have to watch her, see where she put it so we could tell her later. So we've always teased her about it. It's worse now." Because forgetting is consistent with the mother's self-characterization, increased forgetting is interpreted as "just like Mom" rather than as representing senility. "But we can still tease her about it." As the mother became aware of the possible influence of getting older and becoming senile, she became very depressed. Once her mother became depressed, the daughter could sometimes reverse the depression with ice cream or a phone call (to siblings). That usually helped. "She's an ice cream freak."

Another strategy for neutralizing the significance of a situation is to attribute its cause to something perceived as less distressing than its "real" cause. For example, one parent who was continually breaking objects was worried that she was "losing control" of herself and developing a dreaded neurological disease. The daughter, in response, convinced her mother that the clumsiness was due to fatigue caused

by her medications and did not herald the neurological disorder. The daughter was herself fearful that the mother's suspicions were correct. Because of the risk of revealing the true cause of the clumsiness, the daughter did not seek medical help for her mother. She could not trust the physician to collaborate with her protective caregiving activities. The physician was clearly perceived as a threat to successful protective caregiving work.

It was not known, in this instance, whether the mother was developing the dreaded disease. However, awareness of the disease as a possibility provided an important condition influencing the daughter's caregiving strategies. Without such awareness, the caregiving strategies might have been different.

Protective care was perceived as so crucial that, in many instances, caregivers were more willing to risk physical harm to a parent than to risk an insult to the parent's self-image or to the relationship between the parent and the caregiver. Many caregivers were clearly more concerned with protective care than with getting the tasks done or even with preventing physical injury. The successful implementation of instrumental care was often believed to conflict with protective care. The purpose of protective care was generally perceived by caregivers to be of much greater significance than the purpose of instrumental care. In fact, this dilemma and how it was solved formed the basis of most of the conflicts among family members and between caregivers and health care professionals.

The source of this conflict was most often whether protective or preventive and instrumental care were more important.

Primary caregivers overwhelmingly chose protective care, while health care professionals and less involved relatives more often considered preventive and instrumental care more important. The consequence for many caregivers was to limit or prevent the involvement of others in the care of their parents. This decision increased the isolation of caregivers and severely limited their possible use of resources, including nurses and other health professionals. Removing themselves from the health care system and sometimes from the family system was one way to maintain control of the situation.

RELEVANCE TO NURSING INTERVENTION AND RESEARCH

It is clear from the study presented that the efficacy of nursing interventions depends on the nurse's ability to assess family involvement in the care of older parents. Distinctions among the various categories of caregiving activity must be included in this assessment. Failure to recognize the occurrence and significance of protective caregiving can lead nurses to inappropriately assess a family member as uncooperative or noncompliant. Worse still, a family member engaged in protective caregiving often feels most threatened by nurses and other health care providers who focus their efforts on one of the other categories of caregiving. Consequently, family caregivers feel compelled to protect their parent from the intrusion of health care professionals. A carefully informed assessment of the caregiver's perceptions and priorities can prevent the nurse from being perceived as an adversary rather than

an advocate for the patient and his or her family.

The study also demonstrated the importance of nurses pursuing the use of theorygenerating methodologies such as dimensional analysis and grounded theory. Although intergenerational caregiving has been intensely studied with other more traditional methodologies, the instrumental task-based conceptualization of caregiving has gone unchallenged. Failure to ground theoretical categories in lived expe-

rience of the subjects has led to the development of an inaccurate or inadequate knowledge base. The use of theory-generating research is appropriate at all stages of knowledge development. It can be used to generate knowledge in a content area about which very little is known. It can also be used to clarify, develop, or redirect research in a content area about which much is already known, such as intergenerational caregiving.

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