

## **Donner la parole aux aidants naturels qui s'occupent de personnes âgées**

**Pamela G. Hawranik et Laurel A. Strain**

Ce projet avait pour but d'explorer les facteurs susceptibles d'influer sur la santé des aidants naturels qui s'occupent de personnes âgées, tels que l'emploi et le recours aux services de soins à domicile, ainsi que sur la capacité d'assumer cette charge et d'autres responsabilités. Vingt-six soignants ont participé à des groupes de discussion et quatre à des entretiens personnels. Les auteures ont cerné 12 thèmes qu'elles ont répartis en 5 catégories conceptuelles : santé de l'aidant naturel; relations; autonomie; emploi; recours aux services de soins à domicile. D'après les résultats, lorsqu'elle s'ajoute à d'autres responsabilités, la charge des soins peut avoir de graves répercussions sur l'état de santé du soignant. Les participants ont évoqué l'équilibre délicat qui caractérise la prise de décisions entre soignant et bénéficiaire des soins. Nombre d'entre eux ont manifesté le désir d'être intégré à l'équipe soignante proprement dite. L'article se termine sur une discussion des implications de l'étude pour les soins infirmiers.

Mots clés : aidants naturels, personnes âgées, soins à domicile, santé des aidants naturels

# **Giving Voice to Informal Caregivers of Older Adults**

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This study focused on the experiences of informal caregivers of older adults and explored whether employment, use of home-care services, or other factors influence the health of caregivers and their ability to manage their caregiving and other responsibilities. Focus groups conducted with 26 caregivers and personal interviews with 4 caregivers identified 12 themes under 5 conceptual areas: caregiver health, relationships, independence, employment, and use of home-care services. The findings reveal that caregiving coupled with other responsibilities can have serious health effects. Participants spoke of the tenuous balance of decision-making control between caregiver and care recipient. Many caregivers expressed a desire to be included as part of the formal health-care team. Implications for nursing are discussed.

**Keywords:** Caregiving, informal caregivers, older adults, home care, community service use, caregiver health

The prominent role of the family in providing care to a frail older adult is well known. Numerous studies indicate that between 75% and 90% of the care delivered in the community is provided by family members or friends (Kane, Evans, & MacFayden, 1990; Keating, Fast, Frederick, Cranswick, & Perrier, 1999). In 2003 one in five Canadians provided informal care to someone 65 years of age or older (Fast & Keating, 2001; Stobert & Cranswick, 2004).

Providing care to an older adult can affect one's physical, psychological, and social well-being (Cranswick, 2003). Raised blood pressure, immunologic deficits, musculoskeletal problems, and sleeplessness have been recorded (Atienza, Henderson, Wilcox, & King, 2001; Stobert & Cranswick, 2004). Many studies describe the psychological effects of caregiving, such as caregiver burden and depression (Chappell & Penning, 1996; Clyburn, Stones, Hadjistravropoulos, & Tuokko, 2000; Jaffe & Blakley, 2000; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Keating et al. (1999) found that over half of the caregivers to the elderly were employed and a substantial number reported adjusting their work pattern, including arriving at work late, leaving early, changing their work hours, or missing work.

With changing demographics, reductions in hospital stays, and escalating health-care costs, people are being relied upon more to share or assume responsibility for the care of a family member. In the province of

Ontario, for example, family involvement is a condition for receiving home-care services (Ward-Griffin, 2001). Community nurses are increasingly expected to teach, advise, and consult with family members, who are assuming complex caregiving duties. We need more knowledge on how caregiving affects the lives of caregivers, in order for nurses to provide assistance that addresses the needs of both caregivers and elderly care recipients.

The purpose of this study was to explore the experience of caring for an older adult and whether employment, use of home-care services, or other factors influence caregivers' health and their ability to manage caregiving and their other responsibilities.

### **Method**

This qualitative study comprised focus groups and personal interviews with informal caregivers who were providing care to an older adult in the community. Focus groups were chosen as the primary method for gathering information on caregiving experiences. This method allows for direct contact with a number of participants simultaneously, permits an exchange of experiences, and facilitates discussion of perspectives. It also allows the researchers to clarify points and probe for further information. Personal interviews were conducted with individuals who were unable to attend the scheduled focus groups. An honorarium was provided to cover transportation and parking costs. The study was approved by the University of Manitoba's Research Ethics Board.

A purposive sample of individuals caring for older adults was obtained. Inclusion criteria were: the care recipient had to reside in the community and not in an institution, the informal caregiver had to be a family member or friend, and the caregiver had to self-identify as such. Caregiving was defined by the participant; it included assistance with transportation or appointments, daily "checking in" with the care recipient, or assistance with basic or instrumental activities of daily living.

Attempts were made to include male and female caregivers, employed and non-employed caregivers, and users and non-users of home-care services. The recruitment of both male and female caregivers was considered important given the inconsistent findings on how men manage their caregiving situation, how caregiving affects one's health, and whether traditional gender roles influence the caregiving tasks that one performs (Arber & Ginn, 2002; Cranswick, 2003; Jansson, Nordberg, & Grafstrom, 2001; Lauderdale & Gallagher-Thompson, 2002; McGarry & Arthur, 2001). In terms of employment, the results of the General Social Survey (Cranswick, 2003) show that caregiving affects employment in various

ways, with some caregivers retiring early or quitting their jobs in order to provide care (Cranswick, 1997; Fast & Keating, 2001). The use/non-use of home-care services is an important factor. Unpaid caregivers tend to rely on an informal support system, with only a small proportion using formal home-care services despite the stress that is often inherent in the caregiver role (Strain & Blandford, 2003). The inclusion of both users and non-users of home-care services in the present study allowed for examination of the factors that influence the decision whether to use these services and the role that such services play in one's ability to provide care.

Recruitment was conducted by members of the research team located in the community. Posters were displayed at agencies and distributed to staff and informal caregivers who were using agency services. In addition, team members contacted individuals who met the selection criteria, and caregivers themselves were asked for names of other caregivers. Each potential participant received a description of the study, a telephone number to call for further information, and a request to verbally consent to release their name to the research assistant. The research assistant then contacted the caregiver, confirmed eligibility, and arranged for attendance at a focus group or interview at a convenient time and location.

A total of 55 informal caregivers were identified as possible participants, with 30 making up the final sample — 25 individuals were ineligible or unable to participate for the following reasons: unable to be contacted, too busy to participate, or institutionalization or death of the care recipient.

Twenty-six individuals took part in focus group sessions. Eight sessions were held, each with a range of two to five participants. Face-to-face interviews were conducted with four participants at a location and time convenient for them. The small group size and the four individual interviews were necessitated by the difficulty of scheduling a time for participants to meet due to their caregiving responsibilities and other demands.

The focus groups and interviews were conducted using a semi-structured interview guide, with open-ended questions on the influence of employment and service use on the caregiver's health and ability to manage. All sessions were audiotaped and transcribed verbatim. Thematic analysis was conducted using the constant comparative method (Glaser & Strauss, 1967). The transcripts were reviewed separately by the two researchers. Initial codes or keywords were developed to reflect meaning in the data. From these codes, themes emerged. The researchers then jointly reviewed the themes and grouped them into conceptual categories that reflected the caregivers' discussions.

<b>Table 1 Characteristics of Caregivers and Care Recipients</b>		
<b>CAREGIVERS</b>		<b>N</b>
<i>Gender</i>	Female	24
	Male	6
<i>Age</i> (years)	< 50	5
	50–59	10
	60–69	5
	70–79	7
	80–89	3
	range	38–88
	median	59
<i>Relationship to care recipient</i>	Spouse	14
	Child	13
	Other (granddaughter, daughter-in-law, friend)	3
<i>Employment</i>	Not employed	19
	Employed part time	5
	Employed full time	6
<i>Co-resident with care recipient</i>	No	12
	Yes	18
<i>Duration of care</i> (months)	1–24	8
	25–72	11
	> 73	11
	range	1–240
	median	60
<b>CARE RECIPIENTS</b>		
<i>Gender</i>	Female	19
	Male	16
<i>Age</i> (years)	60–69	5
	70–79	12
	80–89	16
	90–94	2
	range	60–94
	median	78

## **Results**

The characteristics of the caregivers and care recipients are shown in Table 1. The caregivers ranged in age from 38 to 88 years. Of the 30 caregivers, 24 were female (of whom 5 cared for 2 individuals), 14 were spouses, 18 lived with the care recipient, and 11 were employed. The duration of caregiving ranged from 1 month to 20 years.

The care recipients ranged in age from 60 to 94 years. Of the 35 care recipients, 16 were male and 13 had some form of cognitive impairment, according to the caregiver.

The most frequently performed caregiving tasks were driving or accompanying the individual to appointments, preparing meals, shopping, and visiting/providing companionship. A total of 19 caregivers used the home-care services of a provincially funded program, the most frequently used being homemaking and personal care. Six caregivers reported purchasing foot care or housecleaning services.

Analysis of the focus group and interview transcripts yielded five conceptual areas with twelve themes. The conceptual areas were caregiver health, relationships, independence, employment, and use of home-care services.

### ***Caregiver Health***

When asked about their health, some participants described psychological, emotional, and physical changes they had experienced since assuming the caregiver role. Three themes were identified in this area. ***Deterioration in health*** was discussed by 14 participants, who identified symptoms such as sleeplessness, crying episodes, weight gain, exacerbation of arthritis, gastric ulcer pain, and sore joints/muscles. A woman who provided care to her husband with cognitive impairment stated, "I got these crying jags and that's why I thought maybe things were getting a little hard for me." This finding is consistent with those found in the literature, where it is reported that caregiving can have negative effects on the health of the informal caregiver such as stress headaches, sleeplessness, chronic back pain, depression, and emotional and physical exhaustion (Cranswick, 2003; Jaffe & Blakley, 2000). In the 1996 General Social Survey (Cranswick, 1997), caregivers reported that the most severe changes in their lives were health-related: 29% reported changed sleep patterns and 21% stated that their health had been affected.

Caregiving sometimes took a ***psychological toll***. Some participants were taking anti-depressant medication but were unable to determine whether their depression was specifically caused by the caregiving situation. Others viewed caregiving as a contributing factor in their depression, in conjunction with other life events such as change of

employment, financial troubles, health problems, or marital difficulties. While caring for a husband with cognitive impairment, one woman had surgery for cancer and a cardiac arrest. She related an experience she had had while in hospital:

*I got up in the morning and I said, "Why not take it all? I've got the pills and why not just take them all?" And that's scary when you stop and think about it, so I was telling [my daughter] about it and, well, she flew down.*

The daughter arranged for her mother to see a psychologist and to have a mental health worker visit her mother when she was discharged from hospital.

Another participant, a single parent, described the multiple responsibilities she had assumed — caring for her parents, helping her three adult children, and caring for an elderly aunt. All of this led to a crisis point: "Sometimes it gets to me...5 years ago I can honestly say...I was close to a nervous breakdown." She confided in her physician on a regular basis for about 6 months and has "felt fine ever since." She admitted that she had taken on more than she could manage but at the same time felt that she needed to help her family.

The third theme was the *sense of responsibility* felt by caregivers 24 hours a day. The care recipient was constantly in the back of their minds. Some participants spoke of being unable to find mental relief, always feeling anxious about the safety or health of the care recipient, even when a hired worker was with the person while the caregiver was at work or taking a break: "I feel responsible for them...I can never quite get them out of my mind. I'm always kind of on call for them."

One woman cared for her cognitively impaired mother, who lived in another community:

*I can't tell you how many times we had to drive back the 60 miles. Either she didn't put the phone right on the cradle so the line is busy all the time and... Did she fall, or did she pull the phone off the hook, or what was happening?*

The emotional tension persisted no matter what the caregivers were doing. Leaving the care recipients for several hours did not provide genuine respite. The literature suggests that prolonged periods of watchfulness and hyperarousal caused by ongoing problems affect one's physical and psychological health (Gottlieb, 1997).

### **Relationships**

The conceptual area of relationships with family and friends included two themes. An *insidious loss of social ties* was described by many partic-

ipants, who spoke of the ways in which caregiving was slowly consuming their time and preventing them from maintaining their friendships. The provision of care itself and their other responsibilities were cited as causes of this insidious process. One spousal caregiver who worked part time described it as “gradual isolation. Your life and part of your activities and part of who you are get dropped one by one, and it’s because it’s too much of an effort.” Before her husband had fallen ill, the couple frequently hosted dinner parties and went out with friends. She expressed disappointment in the fact that her husband was no longer interested in seeing their friends and their friends no longer phoned them or dropped by:

*Your friends go to the ball game but you don’t go because of how far it is, you don’t know where you can park and where you’re going to walk and what you’re going to do. And your friends don’t understand that.*

Going out with the care recipient took a great deal of effort on the part of the caregiver and was perceived as inconvenient for friends.

One woman provided care for both of her parents:

*I’ve only been doing this for a short while but I’m already tired. ...it’s causing a lot of other problems too. ...my personal relationships — I don’t have time for my friends. I’m so tired when I have a moment to myself the last thing I want to do is be on the phone talking, and I’m just really starting to ignore people.*

Her caregiving responsibilities, with both parents exhibiting behaviour indicative of cognitive impairment, were time-consuming and exhausting.

These examples of the effects of caregiving on social and recreational life are supported by the findings of other studies. Caregivers may limit or discontinue their social and leisure activities and other personal pursuits in order to fulfil their caregiving responsibilities (Dunn & Strain, 2001; Jaffe & Blakley, 2000; White-Means & Chang, 1994). In a study with rural caregivers, participants directly connected the burdens of caregiving to not participating in more activities (Jaffe & Blakley).

The availability of other family members did not mean that they were necessarily called upon or considered supportive. The theme **families are not always supportive** was described differently by the participants. In most cases at least one family member lived nearby or could be reached by telephone for advice or assistance. In some situations the caregiving tasks were shared:

*We...do her shopping for her and things like that. And I have a sister and brother. We all take her out once in a while, take her home for a day.*



*We [the caregiver and his wife] are doing, I would say, close to half of it. My sister does a lot too.*

There is evidence in the general social exchange literature that positive social exchanges can dampen or buffer the distress-arousing effects of negative exchanges (Okun & Keith, 1998). Overall supportiveness of the network may buffer the adverse effects of negative social exchanges.

In other caregiving situations, the participant reported frustration and fatigue at being the sole caregiver. A daughter described her brother's lack of assistance:

*I have a brother but you'd never know he was available or around. He doesn't even phone them to see how they're doing. It's a rare occurrence. He's wrapped up with his own family and there's always an excuse.*

There was longstanding conflict in the relationship between these two siblings and little communication between the brother and his parents. Interpersonal conflicts have been described as a form of "chronic strain" whose long-term nature may affect health and well-being (Rook, 2003).

Other participants did not expect family members to assist with caregiving, explaining that family members have their own lives and responsibilities and therefore should not be counted on to help with the care. A woman caring for her husband said, "My daughter and her husband — they work, they've got their house to run... And I don't think you put that onto your kids."

### **Independence**

The theme of the older adult's *desire for independence* formed the conceptual area of independence. Participants described situations in which the care recipient insisted on maintaining his or her independence despite cognitive or physical limitations, causing the caregiver distress. One woman described her mother as fiercely independent:

*Under protest, she got a walker. It's sitting folded up behind her TV covered with a blanket. She also refuses to use her cane. She's very wobbly and for a long time I would grab her arm when we were walking and she would grab it away.*

Another woman expressed frustration at watching her mother continue to lift her father, who was totally dependent upon others for care: "But old people say, 'Don't teach me, I know what I'm doing.'"

Those caring for a parent were often concerned about the person's health and sought to reduce the risk of injury. They proposed some

simple solutions that could reduce the risk of fall or injury but their parent maintained control, unchallenged by the caregiver. Control has been identified as a factor in a caregiver's ability to manage stress and burden, particularly if caring for a family member (Szabo & Strang, 1999; Wuest, Ericson, & Stern, 1994). While Szabo and Strang examine the experience of control by those caring for a relative with dementia, they do not discuss the challenge of caring for someone who exerts control in a potentially unsafe manner.

### **Employment**

Two themes related to employment were evident. Nine of the eleven employed caregivers described **employment as a resource** and as important to their mental health. One participant put it this way: "Work is my sanity. That's my relief. I have to have something that's for me. And my job is me, and that's my outlet." Another said, "I think if I didn't go to work I would climb the wall."

Work was seen as a form of relief from caregiving, even for those whose jobs did not allow for flexible hours. These participants described their work as important to their mental health. The literature on caregiving and employment reveals conflicting findings. Some studies have found that employed caregivers experience less stress than non-employed caregivers (Edwards, Zarit, Stephens, & Townsend, 2002; Orodnenker, 1990), particularly for women with jobs that they find rewarding (Martire & Stephens, 2003).

The experiences of three caregivers can be summed up as **caregiving and employment: a double bind**. These participants perceived their employment as essential but as a distraction from their primary role, that of caregiver, and modified their employment in order to accommodate their caregiving role. A woman caring for a mother with Alzheimer disease adjusted her work hours in order to provide the necessary assistance. Another woman selected a job that would enable her to continue caring for her parents: "I took a cut in pay but my peace of mind and having my folks — it was the best thing that could have happened to us."

The literature on the economic consequences of caregiving indicates that caregiving responsibilities may result in missed days or hours of work or in the postponement of employment opportunities (Jaffe & Blakley, 2000). The General Social Survey (Cranswick, 2003) found that 20% of female caregivers and 13% of male caregivers aged 45 to 54, and 10% of all caregivers aged 55 to 64, reduced their hours of work. A US study found that 16% of caregivers quit their job and 13% retired early (Mature Market Institute, 1999).

### *Use of Home-Care Services*

Five themes described the conceptual area of home-care service utilization. The first theme was **reluctance to use services**. Some participants expressed frustration at the older adult's reluctance to use a service and/or their adamant refusal to accept help from anyone but the caregiver. One woman had tried to convince her father-in-law to accept night respite: "We've tried a lot of these things and he's objected. Once he's there, he's okay, but to get him there is a problem." This participant did not want to force a service on her father-in-law but would raise the topic at various times until he finally agreed. Caregivers in Strang and Haughey's (1998) study, similarly, did not agree to respite services unless the care recipient was willing, and repeatedly tried different strategies to convince the person to accept outside assistance.

Some participants were hesitant themselves to use community services. For some, a personal crisis led them to seek formal assistance. These included a woman caring for both parents:

*I had to be there every day. I was running over there every day and I started to think, "Wait a minute, I'm working full time... Oh, my gosh, how much more can I take?" I arranged for her to go through the home-care system.*

Some of the caregivers did not seek and obtain formal services until they reached a crisis point and were overwhelmed. Other researchers have similarly found that families often use respite services as a last resort when they are under a great deal of stress (Chappell, 1992; Strang & Haughey, 1998).

**Lack of knowledge** about available services was evident in the case of both novice and long-time caregivers. A participant whose husband had urinary incontinence had been doing laundry every day, unaware that pads for incontinency were available free of charge through a publicly funded home-care program. A granddaughter expressed interest in attending a support group but did not know that there were support groups for family caregivers. These caregivers apparently assumed that no assistance was available and received no information about home care from acquaintances or family members. Evidence concerning why caregivers underuse or fail to use formal services remains inconclusive (Connell, Kole, Avey, Benedict, & Gilman, 1996; Morgan, Semchuk, Stewart, & D'Arcy, 2002; Strain & Blandford, 2002).

Over half of the 19 participants who received publicly funded home care related experiences best described as **struggling to obtain the best fit**. Frequent changes of staff, lack of knowledge and inadequate training of staff about the client's health, and inconsistent performance by service

providers were frustrating for the caregiver and perceived as disruptive for the care recipient. “My biggest problem with my folks has not been my folks,” said a woman caring for both of her parents, “it has been with home care; they used to send me six different people in a week.” For some caregivers, use of home-care services meant being late for work because they needed to orient each new person, while other caregivers cited increased anxiety and agitation in the care recipient. The staffing situation did not change until they persistently demanded continuity (no more than two different workers per week).

A related concern was the lack of preparation of home-care staff regarding the particular client. Some participants said that staff did not know the nature of the care required nor whether the care recipient was cognitively impaired: “The girl we have now didn’t know he had dementia when she came in. I had to tell her. And she doesn’t really know how to handle it yet.” This problem tended to be cited by those caring for a person with cognitive impairment. The worker was not aware of the cognitive impairment and did not know what to do. In the McGee, Tuokko, MacCourt, and Donnelly (2004) study, similarly, focus group participants identified a lack of knowledge and skills on the part of community-care providers in the area of dementia, understanding and managing difficult behaviours, and communication.

The fourth theme was a *good match*, or a perception that services met the needs of the care recipient and the “best” array of services was in place. Caregivers frequently saw themselves as gatekeeper, mediator, and advocate for their family member. If the caregiver felt that services did not address the needs of the care recipient, or if the care recipient did not like the worker or the services, then the caregiver tended to be dissatisfied with the home-care situation.

Finally, some participants spoke of wishing to be *part of the team* and to be included in the decision-making about the care of their family member. They saw themselves as a vital link between the older adult and the health-care system. They knew the person’s needs and wished to ensure that health professionals were aware of and addressed these needs:

*I always made sure we had a family meeting. We need an understanding from the health-care team. And maybe it’s the system all in all that we talk about family care, whatever it may be, but nobody is walking the talk right now. It’s all individualized care.*

Some participants expressed anger and frustration at being excluded from assessments and care planning. They felt that vital information on the behaviours and likes and dislikes of the care recipient was being overlooked and that respectful and appropriate individualized care was not being provided. This finding is consistent with that of Morgan et al.

(2002), who report that informal caregivers in their study criticized the practice of home-care providers conducting assessments of persons with dementia in the absence of the caregiver or someone else knowledgeable about the person, especially since the person with dementia often denied having a problem. Other researchers suggest that conflicts can arise when service providers fail to recognize a caregiver's expertise (Duncan & Morgan, 1994) or when there are discrepancies in role expectations (Ward-Griffin, 2001).

### **Implications for Nursing**

The discussions with the 30 informal caregivers contain valuable lessons. Many participants spoke of physical changes and mental stress, particularly when caregiving took place concurrent with other responsibilities and various life events. This highlights the need for nurses to take caregivers' situation into consideration, by, for example, assessing their physical, mental, emotional, and spiritual health, discussing their other responsibilities, recognizing that employment can have both positive and negative effects, and outlining the potential health effects of caregiving and other responsibilities.

Several issues emerged with regard to the use of home-care services. Caregivers' reluctance to use services and lack of awareness about their availability demonstrate the importance of reaching out to individuals who are caring for older adults in the home setting. Some participants expressed frustration with their exclusion from assessment and care planning. Further research is needed to determine if and when caregivers wish to be part of the planning team and the nature of their potential involvement. Our findings suggest that nurses should ask caregivers if they would like to be involved in the decision-making process. In addition, the caregiver's assessment of the situation should be considered. Role negotiation between the nurse and the caregiver, with clear delineation of roles and responsibilities, may be necessary. The policies of community agencies may need to be modified to address the potential dual role of the caregiver as a client and as a member of the planning team. Nurses, as client advocates and agents of health promotion, can play an important role in modifying the focus of the system and of agency policies to include greater input by caregivers and clients.

Some participants raised the issue of control. This area requires further exploration by both practitioners and researchers. The balance between the desire for the care recipient to maintain control and independence and the need for the caregiver to encourage or assume control should be discussed with the caregiver. Certainly, independence and self-care ought to be encouraged. However, the safety of the older adult and perhaps the

caregiver as well must be considered and assessed. It may be that informal caregivers are aware of and accept the self-reliance and independence of the current generation of older adults and are prepared to respect and honour them. Nurses should assess the delicate balance between the need for older adults to maintain control and the need for them to relinquish control. Nurses may have to help the informal caregiver to identify which decisions can safely and realistically be made by the care recipient. Research examining the point at which the caregiver decides that the care recipient cannot or should not exert control, and situations in which the caregiver overrides the recipient's insistence on maintaining independence and control, would increase our understanding of the dilemmas faced by the caregiver as the recipient progresses from independence to dependence.

While the findings of this research shed light on important issues from the perspective of caregivers, the limitations of the study must be acknowledged. The sample size was small and the caregivers volunteered to participate because they wished to share their experiences. Few male caregivers were recruited, which is consistent with the difficulties encountered in other studies (Neno, 2004). The type of experiences discussed by the caregivers in this study should be explored further with larger and more diverse samples.

The findings highlight a number of important issues raised by informal caregivers of older adults and offer insight into caregivers' perceptions and their desire for more consideration and control. Nurses and other health-care providers ought to listen to informal caregivers, for these people play a key role in the care and well-being of the elderly and constitute a vital link between older adults and the health-care system.

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