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Caregiver role development in chronic disease: A qualitative study of informal caregiving for veterans with diabetes

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Abstract

Objective: Support for chronic conditions such as diabetes from friends and family positively influences health management and outcomes, but limited data exist on how and why caregivers assume specific support roles for otherwise independent aging adults. We conducted a qualitative study to examine the nature of caregivers roles in supporting Veterans management of a chronic condition and caregivers reasons for assuming those roles, using Type 2 diabetes as an example.

Methods: Thirty-two interviews were conducted with Veterans with Type 2 diabetes (n 20) and their caregivers (n 12). Two coders independently analyzed interview transcripts using a thematic analysis approach.

Results: Three central roles of caregivers in diabetes management were described: direct care support, memory support/care organizer, and advocate. Three explanations for assuming caregiving roles emerged: changes in patient health, natural evolution of family roles, and caregivers health care experience or training.

Discussion: Understanding what roles caregivers fill and why is critical to designing services to support caregivers in helping improve chronic health condition management for aging adults.

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N/A

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Roles; self-management; qualitative

Introduction

Six in ten American adults have at least one chronic condition, and this number continues to rise.¹ Like many chronic conditions, diabetes requires complex medical management and challenging daily self-care, often requiring following regimented eating plans, monitoring sugar levels, organizing daily medications, and coordinating medical care. In addition, many adults with diabetes acquire other comorbid chronic conditions as they age,² further complicating self-care. Because of this complexity, successful diabetes self-care can be difficult to achieve and sustain without self-management support, defined as the help given to people with chronic conditions that enables them to manage their health on a day-to-day basis. The American Diabetes Association³ recommends collaborative, team-based approaches to facilitate effective self-management support for adults with diabetes.

Increasing evidence recognizes the importance of informal caregivers, or unpaid family members and friends (hereinafter referred to as ‘caregivers’), as key supporters for aging adults’ self-management of chronic conditions.⁴ Fifty to seventy-five percent of people with diabetes have a caregiver involved in their healthcare.^{5,6} These caregivers are often partners/spouses, adult children or siblings, but other relatives, neighbors, and friends may also provide regular care and support. Caregiver involvement in patients’ diabetes care is associated with more successful self-management and better health outcomes. For example, higher levels of caregiver support are associated with better glycemic control and lower mortality.^{7,8} Higher caregiver support has also been associated with less diabetes-related distress and increased patient self-monitoring, use of technology aids to manage health, and participation in decision making during care appointments.^{9–12} Because of this evidence, the most recent National Diabetes Education Program priority plan calls for empowering caregivers to assist people with diabetes. Despite these recommendations, recent studies reveal that a minority of caregivers receive education or training related to their caregiving role,¹³ and healthcare providers are often reluctant to share critical patient information with them.¹⁴

One knowledge gap limiting the provision of appropriate education and training to caregivers is a lack of understanding about what roles caregivers of aging adults with chronic conditions assume and why. There is reason to believe that caregiving roles are different for patients with different types of health conditions.¹⁵ For example, while caregivers of adults with cancer help with symptom management and emotional support,¹⁶ those caring for adults with dementia more frequently assist with hands-on personal care tasks such as bathing, feeding and toileting, especially as the condition progresses.¹⁷ As a chronic disease that affects many organ systems and requires complex management yet can be diagnosed at a relatively young age and controlled to stave off morbidity—diabetes is an example of a chronic condition in which patients may benefit from caregiver involvement even while they remain functionally independent. Furthermore, as a patient with diabetes

ages, a caregiver who initially focused on helping with diabetes may go on to fulfill other caregiving roles as diabetes-related complications or other health conditions develop.

To improve how the healthcare system supports caregivers of adults with diabetes, the roles they assume and the reasons motivating their caregiving roles must be better understood.

The purpose of this study was to explore what roles caregivers assume in supporting adults' chronic health condition management and specific reasons for fulfilling these roles. Information gleaned from this study may help healthcare providers target support and training for caregivers' roles as their loved one's age and their needs change.

Methods

Design

The design of this study was informed by a qualitative descriptive approach, which entails a low-inference interpretation of data to uncover the basic facts of an experience.¹⁸ We follow reporting guidelines for qualitative research outlined by Tong, Sainsbury, & Craig.¹⁹

Participants

We originally planned to recruit 30 Veterans with 'high-risk' Type 2 diabetes and a specified caregiver using purposeful random sampling.¹⁸ 'High-risk' Veterans with Type 2 diabetes were targeted because the selfmanagement demands for these individuals tends to be complex with more medications, self-testing, healthcare system interactions, etcetera. Participants were recruited from a Midwestern VA health system registry of patients identified as having 'high risk' diabetes, defined by, 1) a diagnosis of Type 2 diabetes and 2) either poor glycemic control (defined as last A1c >9 and age > 55, or last A1c >8 and age 55) or poor blood pressure control (defined as last BP >160/100, or mean BP over the prior 6 months > 150/90). A random sample of patients from the registry were contacted by phone to nominate a 'family member or other caregiver' who was an adult family member or friend to whom they have spoken regarding their diabetes at least twice in the past six months and involved in their diabetes care. Patients were asked if their family member or other caregiver assisted them in one of the following ways: "remember to refill or take your medicines, remember to check your sugar, help you decide what to do when your sugar numbers change, or come with you to medical appointments." Because our focus was on caregiver roles for functionally-independent patients, potential participants were screened for and excluded if they had a diagnosis of dementia or reported requiring help with basic activities of daily living (BADLs) (e.g., dressing, bathing, grooming). Interested and eligible patients were then asked to identify the caregiver who was most involved with their diabetes care to be invited to participate in a separate interview. Eligible caregivers could either live with or apart from the patient, had to be at least minimally involved with the patients' healthcare (e.g., talk to patient about their health) at least weekly, and were excluded if they received pay for caring for the patient. Patients were able to participate in interviews whether or not the invited caregiver also participated. This study received Institutional Review Board approval, and all participants gave verbal or written consent to participate in this study.

Data collection

At the start of the study, participants responded to closed-ended questions regarding the nature of their relationship with their caregiver (e.g., spouse/partner, parent-child), residential proximity to their caregiver, as well as a validated health literacy screening instrument developed in Veteran populations²⁰ to capture patient health literacy. During the open-ended interviews, patients and caregivers were asked about their perceptions of caregiver involvement in specific diabetes management tasks, including involvement in patients' medical appointments and helping patients to navigate the healthcare system. At the end of interviews caregivers were asked about any other ways they wish they could help, and whether they felt nervous about any ways in which they help their loved one. Semi-structured interviews were conducted with patients and caregivers separately by members on our study team (AR, CR, and JF). One member was responsible for conducting the interview and another study member served as a notetaker (see Online Appendix for Interview Guides). On average, interviews lasted 49 minutes, with a range of 23–81 minutes. Interviews were completed either face-to-face or over the telephone, and were audio-recorded, transcribed verbatim and verified, then analyzed in NVivo 12 PRO for Windows.

Data analysis

Guiding framework.—To help structure our thematic analysis,²¹ we used the DECAF (D Direct Care Provision, E Emotional Support, C Care Coordination, A Advocacy, and F Financial) framework.²² DECAF was originally developed to increase recognition for roles caregivers take on in care planning and execution during the hospital-to-home transition, but is relevant to the situation of caregivers helping functionally independent adults with diabetes due to the range of caregiving roles it recognizes. In the framework, *Direct Care Provision* refers to hands-on support with daily activities which can include mobility, dressing, medical and nursing related tasks like wound care and medication management, and personal device use. *Emotional Support* is commonly described as empathy and compassion provided to the care recipient. *Care Coordination* is defined as initiating, managing and maintaining healthcare services and supports. *Advocacy* is directed towards empowering individuals to obtain resources. Lastly, *Financial* support is defined as help with planning and using fiscal resources. The DECAF domains provided a framework to organize coding and themes regarding how caregivers become involved in specific roles that support those with diabetes.

Analysis.—We used deductive coding, guided by the DECAF framework, as well as an inductive approach focused on the caregiver-patient relationship and challenges faced by caregivers. Starting with open coding, the study team read and reread the interview transcripts multiple times to develop and refine coding categories that derived from the data. The lists of categories were then sorted and grouped according to similar content under higher order headings, with reductions of the data by content areas into broader categories for coding. Then, two coders (BF and KR) independently coded 20% of the transcripts and met to resolve any discrepancies using a negotiated consensus process, with adjudication from AMR when needed. The primary coder (BF) coded all of additional transcripts. Coded text was interpreted and grouped into overarching themes. Finally, we examined patterns

and connections between each theme and attributes of patient and caregiver relationship and residential status, and patient health literacy.

We used internal validity strategies recommended by Creswell²³ to enhance the credibility of findings: (a) multiple data sources (i.e., interviews with both patients and their caregivers) were included; (b) codes and definitions were continuously examined, modified, and consistency in their application was obtained; and (c) study members regularly discussed qualitative findings to strengthen dependability of interpretations.

Results

Participants

Thirty-two adults consented to participate in this study: 20 patients with high-risk diabetes, 11 paired caregivers and 1 caregiver of an adult with diabetes who was not able to be interviewed. These participants represented a total of 21 patient-caregiver relationships. We preliminarily analyzed data and updated our codebook until we reached thematic saturation, the point at which no new themes, or significant information about current themes, arose in patient and caregiver interviews. Of the 21 relationships represented by our participants, the caregiver was a spouse or partner in 11 (52%), an adult child in 8 (38%) and another relative or friend in 2 (10%). Over half (n 15) of the relationships described were of co-habiting patient-caregiver pairs. Only two caregivers lived more than 100 miles from their care recipient. Three patients (15%) screened positive for low health literacy.

While each group of participants emphasized different elements of caregiver support in diabetes self-management, the groups were similar in their overall views of what roles caregivers assume and why. Therefore, the data from both adult patients and caregivers were combined for the analysis. Pairs of participants were matched by the last 3 digits of their study ID numbers.

Caregiver roles in supporting diabetes self-management

Adult and caregiver participants described three central roles of caregivers in diabetes self-management that align with the DECAF framework: *direct-care support, memory support and care organizer, and advocate*. Participants did not discuss or describe diabetes support roles in relation to the Emotional Support or Financial domains from the DECAF framework.

Direct care support.

Several direct care responsibilities that were commonly assumed by caregivers included helping choose or prepare healthy food, helping patients be more physically active, driving them to healthcare appointments, and carrying out specific medical or nursing-related tasks like wound care. For example, one patient shared, “My wife is very involved in my food intake; she makes sure that I don’t sneak things into my diet that I shouldn’t have” (PI 134). Likewise, a caregiver noted how she has learned to modify recipes for her loved one that has a sweet tooth:

I make him sugar free banana cream pie so that way he has his sweets. It is important to teach them how to cook using what is out there because a lot of that artificial sweetener is really good when you cook with it (C2098).

Related to exercise, one patient shared that he and his wife exercise together daily (PI070). Caregivers regularly shared that they are chiefly responsible for driving their loved ones to medical appointments. Specifically, one caregiver said, “I have no choice but to be there for him during appointments and whatnot, I drive him most of the time” (C2126).

Specific medical or nursing tasks that required help from a caregiver, which were shared by many participants, included changing wound dressings and giving insulin shots.

The biggest time that she helped me recently was when I had that big sore on the bottom of my foot and I couldn't reach it and every day it had to be, the dressing had to be taken off and had to be cleaned and a new dressing put on, and she did that twice a day for me and that was the biggest help, that saved my foot (P1008).

Sometimes I draw up his insulin for him and give him his insulin shot; that took a lot, but I can do it now. I learned how to do that just by watching him (C2043).

Although the patients we interviewed did not regularly need help with BADLs, they sometimes had temporary needs for this kind of assistance.

Like when he had his knee done, I was over there every day, gave him a shower, did everything he had to do because he couldn't stand up . So just a different role than I have had to play before, that's for sure (C2008).

Memory support and care organizer.

Managing diabetes successfully requires significant care organization and coordination of multiple types of interactions with the healthcare system. These interactions can include healthcare appointments, eye exams and blood tests, and medication regimens and refills. Participants frequently recognized caregiver roles in care organization, such as helping with tracking and scheduling appointments, taking notes before and during healthcare visits, and making lists of current medications.

I write his appointment dates on the calendar and then I remind him, like I'll say, “Well you know, I told him you've got an 8:30 appointment Monday,” and I keep reminding him of that for a couple of days (C2100).

When I am in the exam room with him, I can hear the whole story and if there is a medication change or if he is supposed to do something different. I can remember a lot of things that they [doctors] are going to tell him. Two ears are better than one (C2001).

One caregiver shared, “He tries to prepare himself and if he's got a list of questions for the doctor, he'll tell me to sit down and I'll write them down for him” (C2100). A patient explained how his caregiver helps him stay organized, “My daughter takes notes during visits and gets printouts of current meds list [she] helps keep track of everything” (PI 115). Patients also mentioned how caregivers help them track blood sugar readings in a logbook to go over with their doctor during visits.

Advocate.

Due to changes in diabetes regimen, or new symptoms from diabetes, there are many opportunities for shared decision making with healthcare providers. One caregiver shared that she knows when and how to contact her husband's doctor if he is having problems:

I've called after hours, where we've wondered whether or not we should be coming in, where his sugar has been high and stuff like that (C2043).

A patient shared how his wife steps in to help direct care:

She'll call to make an appointment or if I am on the phone she will say, let me have the phone to talk to the doctor and ask questions. I'll even say, hey, let me give the phone to my wife, she knows all this stuff better than I do (PI 123).

Several participants described experiences where the caregiver advocated on behalf of the patient when experiencing serious health complications linked to diabetes.

I've had three strokes, my boy has taken me to the hospital all the time. I think the first time they [doctors] were going to send me home at the emergency room, but my boy wouldn't stand for it. Then they admitted me (PI043).

Reasons for caregivers assuming diabetes self-management support roles

Our iterative analysis revealed three themes that explain why caregivers started to assume the previously described roles in supporting diabetes self-management: *changes in health, natural evolution of roles, and education and care experience.*

Changes in health.—Participants frequently mentioned recognizing signs or symptoms that the patient's health was deteriorating as a reason for taking on care roles. For example, one patient shared that he was starting to not be able to remember things as a reason for involving his wife in appointments. One caregiver shared that a new requirement for her loved one to use insulin injections forced her to learn a new skill: "I helped my dad give him shots, so it's amazing what you can do when you have to" (C2070). Patients expressed gratitude for their caregivers stepping in to help them when other health challenges such as pneumonia, congestive heart failure, and surgery affected their ability to manage their diabetes. For instance, one patient described a time where he was having difficulty breathing:

I was at home, called my son and he was on his way to work but then came over to get me to the hospital. I am very accepting of my son's involvement in my health, without him I would be under by now (P1032).

Some caregivers acknowledged uneasiness about knowing how or when to step in and help as their loved one aged or health status worsened:

It is hard trying to get him to keep doing things. . . And the walking, it's getting really bad. It's getting to the point where it's a chore for him to walk, even with his little roller *caregiver tearful at this point*). Things are just changing as far as how much he can do for himself (C2008).

Natural evolution of roles.—Many participants expressed that caregiving roles supporting diabetes management originally started as natural outgrowths of non-health related things caregivers were already doing with loved ones. For instance, “We [caregiver and husband] have always worked as a team, that is the way we just do things. You just go through stuff together whether you want to or not” (C2043). A patient shared, “I take care of my business, but she [caregiver] is right there making sure it’s right. It’s something, just like the pills, income, and all that stuff. She just takes care of all that” (PI 128).

Many of the participants in this study described diabetes caregiving roles as natural extensions of roles taken on as part of living in a household together. Other caregivers often assumed roles because they lived nearby and were already in a routine of stopping to check on their adult loved one. For example, one caregiver shared that he takes his father shopping for healthy food the day he does his own errands as his father lives alone and rarely leaves his house (C2087).

Education, healthcare training or experience.—Patients commonly shared that they turn to specific caregivers for help in managing their diabetes because of education or experiences in healthcare. For example, a caregiver shared how her experience helped her figure out what to do to help her husband monitor his diabetes: Years ago, I went to school for nursing. I didn’t finish it. But then I actually worked in the nursing home for a very long time. You just pick up things here and there that help you establish a routine. Like every morning we use the meter together to check his sugar (C2043).

Another patient stated about his wife, “When I get a little helpless, she’ll help. Some things I just don’t understand, she got a little more education than I have so I use her for my reference” (PI 128). Caregivers with healthcare experience often got involved even when others were available to the patient in the same household. For example, one caregiver helped his father -even though his father lived with a spouse-because the caregiver had medical training, “I am a licensed paramedic and when he has a hard time understanding some of the words that they [healthcare providers] use, I try to help out with that” (C2098). Many interviewees also described caregivers getting involved because they were more familiar with the technology. For instance, one patient described how he planned to have his caregiver [son] help him with online healthcare platforms:

I want to use the computer to help me make appointments, look at my records, and to use the pharmacy. I don’t use the computer now though, so it will be up to my boy. I have a computer, but he will have to get me on it. Like show me how to login and all that stuff (PI 100).

Relationships among caregiver roles and participant attributes

Using the close-ended data collected prior to the interviews, our iterative analyses demonstrated differences in caregiver roles related to patient-caregiver relationship, residential status, and patient health literacy. Compared to child caregivers, spousal caregivers assumed more direct care roles like helping choose healthy food and adjusting activity based on blood sugar levels. For example, a patient shared, “my wife [caregiver] is constantly overlooking my eating. She’ll say, ‘hey, you are putting too much salt on that’

(PI 134). In addition, spousal caregivers frequently described helping their loved ones with remembering day to day self-management tasks. Child caregiver roles more often focused on assisting parents with organizing and advocating for care. For instance, a daughter described how she helped her father via the phone:

When I found out he [patient] was in the hospital, I was able to call them up and say this is [caregiver name] and I am calling in regards to [patient name]. After I confirmed the last four of his social, I was able to cancel his appointments . And because I am not very familiar with a lot of what the VA does, I would call and tell my dad to be sure to ask them about services and all of the benefits (C2001).

Child caregivers more often shared that they increased their support for their parent when a change in health occurred, as opposed to spouses whose roles seemed to more naturally evolve.

Caregivers who lived far (e.g., more than 20 100 miles) from their adult loved one more frequently described helping with care coordination rather than direct daily care roles. These caregivers also more often shared the need to step into the care organizer and advocate role when their loved one had an unpredictable change in their health. For example, one patient shared about her daughter who lived at a distance, “When the stroke came, then she [daughter] started taking over my meds—she was very, very conscientious about what was going in the pill box. She would read the pill explanations to me and put them in the proper order” (PI043).

Lastly, patients with low health literacy more often described receiving support from caregivers in organizing and advocating for their care, completing medical and nursing related tasks, and explaining their medications. One caregiver of a patient who screened positive for low health literacy described how he helped make sure his dad [patient] understood a medication question during a routine appointment:

He had a few problems trying to understand some of the technology and some of the words that were used during one of his appointments. His last cardiologist appointment that I went to, the doctor was trying to ask him about his Lasix and how it was working; I had to rephrase the question for my dad (C2100).

Discussion

This study explored what roles caregivers fill and why in supporting care management for Veterans with Type 2 diabetes. We found that caregivers of adults with diabetes assume support roles related to helping remember healthcare tasks, providing hands-on support for daily activities, and coordinating communication and services with healthcare providers. Caregivers described assuming these roles as a natural extension of pre-existing tasks handled together, because their loved one experienced new symptoms or diagnoses, or because the caregiver had previous healthcare experience or training that allowed them to help with the increasingly complex health situation. We also saw evidence that diabetes care roles were often shaped by the proximity of the caregiver to their loved one, their pre-existing relationship, and the patient’s health literacy level. The findings in our study give rich context to previous quantitative studies^{5,7,8} that demonstrated that

caregiver involvement in diabetes is common and can have significant effects on adults' diabetes management and outcomes. To our knowledge, few qualitative studies have been conducted that describe how caregivers support the self-management of diabetes, despite its high prevalence and complex management requirements. Indeed, a qualitative systematic review that explored the role of family members in supporting self-management of chronic conditions included only one study that described experiences with diabetes, specifically among Turkish migrants.^{24,25}

We found that caregivers provided a wide range of hands-on support with daily activities to adults with diabetes, aligning with the direct care support domain in the DECAF framework, and consistent with findings from other quantitative studies in diabetes.^{26,27} While other studies have demonstrated that caregivers help with self-care tasks like diet or exercise,^{28,29} our findings go one step further to illustrate how caregivers provide this instrumental support. We found that caregivers help prepare healthy food, go on walks with their loved one, drive them to healthcare appointments, and carry out specific wound care tasks. Consistent with other studies on the care support preferences of aging adults,³⁰ we found that spousal and proximally located caregivers are often those that provided direct care tasks because of ease of access to their loved ones. Yet, given that many caregivers will become increasingly involved with diabetes management from a distance due to advances in technology and changes in family structure,³¹ further development of tools like activity trackers and menu planning applications may help more distance caregivers become involved with these activities in the future.

We found that caregivers were providing memory support while coordinating care for adults with diabetes. Caregivers shared how they frequently helped their loved ones remember to fill medications and follow instructions after a care visit. Providing memory support to adults with diabetes may become an increasingly important caregiving role as patients age, as diabetes care becomes more complex,³² and patients with diabetes are more likely to experience cognitive decline.³³ Healthcare providers can help caregivers learn to apply strategies like mnemonics and visualization charts to better support their loved one's memory for diabetes task completion. So far, many of the family-based diabetes interventions that have been designed and tested in diabetes focus on family support for a healthy lifestyle including healthy eating and physical activity.^{34,35} Future interventions could consider adding cognitive assessments and memory-boosting strategies, particularly for medication and self-testing regimens, to these existing interventions.

Our findings and others'^{36,37} suggest that an advocacy role is common for caregivers of adults with chronic conditions. While both spousal and adult child caregivers described advocating for their loved ones, adult child caregivers shared needing to step in and assist more when their parent experienced a change in health status. This implies that adult patients and their spouses may be more amenable to adult children taking on an advocacy role in times of 'high need'. Roberto and McCann³⁸ similarly found that adult women with chronic conditions generally chose not to involve their children unless there were emergency situations. Healthcare providers can try to engage adult child caregivers during these critical care points, and look for ways to support the continued involvement of these 'new' caregivers after the health crisis is over.³⁹ Additionally, adults with low health literacy

described how they relied on their sons or daughters for help with calling their doctors and managing care online because of their experiences with healthcare and technology. While we did not directly compare patients' stated support needs to caregiver roles, these findings suggest that caregivers are responding to perceived patient needs. Our findings suggest that healthcare providers should be more open to facilitating the sharing and tracking of health information between patients and their caregivers, and be open to using diverse modes of communication such as online personal health records and videoconferencing platforms. To help ease access to health information among caregivers, future research can explore which ways are most effective in helping patients identify and record who they want involved in their care and how they want their electronic information shared with those caregivers.

Limitations

This study has several limitations. Recruitment of one caregiver per patient meant that we did not account for all caregivers providing support, and thus, did not capture the experiences of all of those caring for the patients in this study. Future research is warranted that explores the dynamics of the full family network in supporting diabetes self-management. In addition, our study included only Veteran patients, with most patient participants being male and most caregivers being female. Our findings, therefore, may not encompass the experiences of female patients and their caregivers, particularly as caregiving roles can differ by gender of the care recipient and caregiver. The absence of information related to the emotional and financial domains of the DECAF framework may have resulted from the structure of our interview guide. Participants were asked few direct questions about these domains and these questions were towards the end of the interview, when respondents may have been experiencing respondent fatigue.

Conclusion

This study is one of the first to qualitatively describe how and why caregivers care for adults with Type 2 diabetes. Our findings describe how adults with diabetes turn to caregivers for hands-on assistance with daily activities, coordinating and remembering healthcare tasks, and advocating for care. In response to these findings, healthcare providers can tailor caregiver education and support to the specific roles and motivating factors underlying the caregiving relationship. Healthcare providers can also look for increased caregiver involvement at times when health status changes, and expect that those assuming caregiving roles may not be the patients' spouse or partner, but others in their family who have relevant healthcare experiences and may live at a distance. Future qualitative studies could generate additional data further connecting the known positive effects of caregiver roles in supporting diabetes self-management to specific explanations and actions. Information gleaned from this study may guide research and practice focused on assessing and tailoring support for caregivers in diabetes care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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