

Intervention is Urgently Needed to Address Poor Awareness of South Asian Family Caregivers for Dementia Care: A Qualitative Study

ABSTRACT

Introduction: “The National Dementia Strategies” in Canada emphasizes improving the knowledge of formal and informal caregivers for better care for the person living with dementia.

Aim: This study aimed at exploring awareness and the attitudes of South Asian Bangladeshi family caregivers towards dementia care.

Methods: It was purposive sampling and a qualitative study. The study included 45 family caregivers (>55 years) for the face-to-face interviews in Toronto, Ontario. The study used semi-structured questions. The duration of the data collection was between February and March 2020.

Results: The study included the three areas related to dementia, such as a) the awareness of dementia, b) awareness of prevention and treatment as well as the awareness of caregivers about what is needed for better dementia care, and c) attitudes of caregivers towards dementia care. Many caregivers described dementia as memory loss and forgetfulness. According to the caregivers, anxiety, depression, and aging were the risk factors of dementia. The caregivers commonly perceived dementia as an unpreventable and incurable disease. Moreover, many caregivers did not know about the appropriate health providers who diagnosed and treated dementia, and they were not aware of non-pharmacological care of dementia. The caregivers perceived dementia as a shameful disease. They would not go for diagnosis if they had risks for dementia and would hide their dementia after diagnosis. Many caregivers confessed that training was essential to improve knowledge about dementia, but they did not want to be a caregiver for the person living with dementia.

Conclusion: The South Asian Bangladeshi family caregivers had not enough awareness about dementia, prevention, and treatment. Dementia was associated with shame, and they had less interest in dementia care. Urgent educational training is needed in their language to improve knowledge, reduce stigma, engage them in dementia care, and achieve the goals of the National Dementia Strategies.

Keywords: *family caregivers, awareness, dementia, stigma, memory loss, anxiety, depression*

1. INTRODUCTION

Approximately 55 million people are living with dementia worldwide [1]. The numbers will rise to 152 million by 2050 [2]. Moreover, it estimates that 9.9 million people develop dementia every year, but many dementia cases are underreported worldwide [2]. The current population in Canada is about 380 million [3] and estimated dementia cases in Canada were almost 5.6 million, and it will rise to 9.4 million by 2031[4]. Every year, approximately 78,600 new cases are diagnosed. This incidence is 14.3 new cases per 1,000 in the senior population (65 years and older), so it is a public health concern in Canada [5, 6]. By 2031, it projects that the total yearly health care costs for Canadians with dementia will have doubled from \$8.3 billion to \$16.6 billion [5]. It includes health care costs, lost wages, out-of-pocket expenses of family members. The National Dementia Strategies of Canada launched in 2019. One of the core objectives of the strategies includes raising awareness among the general population, health care professionals, and formal and informal family caregivers [7]. The government and local community organizations work together to support and provide services to create awareness in general populations, professionals, and caregivers to improve the quality of life of the persons living with dementia.

Family caregivers are potential sources of care in Canada because they provide care to family members or friends living with a chronic condition, including dementia and health problems related to an older age. About 7.8 million Canadians are family caregivers [8]. Family caregivers do not have any formal training to take care of family members and are unpaid, invisible, and their support is rarely recognized [10, 11]. The family caregivers are the first person who can notice any symptom of the illness of family members. Awareness and knowledge of family caregivers are essential to managing any disease, including dementia. Understanding the symptoms of dementia earlier could provide family members with better care without delay. Usually, the family caregivers help the person living with dementia in their daily activities [12, 13, 14, 15,16]. If the caregivers' knowledge is not adequate, caring for persons living with dementia is not enough.

India, Pakistan, Sri Lanka, Nepal, and Bangladesh are South Asian and are the visible minority group in Canada [17]. One study in Canada showed that the South Asian family caregivers delayed seeking care for the persons living with dementia as they had low awareness of dementia [18.]. The South Asian Bangladeshi family caregivers are not exceptional because they have a language barrier, so they might not have access the dementia resources [19]. The National Dementia Strategies' objective is to reach out to formal and informal caregivers for creating awareness among the caregivers. However, information is lacking about the South Asian Bangladeshi caregivers regarding dementia awareness and care for the person living with dementia. Thus, the study was relevant to exploring the South Asian Bangladeshi family caregivers' understanding of dementia. Significant proportions of family caregivers in Canada are aged above 55 years, and they spend substantial time with their spouses and other family members as caregivers [9]. Thus, the study had included South Asian Bangladeshi family caregivers aged over 55 years. The study had two broad research questions: a., do they have enough awareness of dementia, prevention, and treatment? b. what attitudes are towards dementia care? The federal and provincial governments highlight improving the knowledge of dementia across Canada, so the findings of the study would be helping improve awareness and to change the attitudes towards dementia care if needed.

2. METHODS

2.1 STUDY DESIGN

Bangladeshi-Canadian Community Services (BCS), an ethnic non-profit organization, has been serving the South Asian Bangladeshi community in mainly Crescent Town and Oakridge neighborhood (hence called Taylor Massey neighborhood) in Toronto since 2000 [19]. This neighborhood has a higher concentration of Bangladeshi communities in Toronto [20]. Around 310 community members who were 55 years and above registered with BCS from 2017 to 19 for receiving services like government information, health workshops, medical escort services, home services, and social connection. The study recruited the senior caregivers using the registered list. We applied qualitative research. Qualitative research could explore detailed perspectives, including experience, meaning, beliefs, and attitudes [21]. Moreover, this study did not have enough caregivers for the quantitative research to measure the statistical outcomes. The study applied structured questionnaires for socio-demographic profiles and semi-structured questions for understanding the perspective (in terms of dementia, prevention, treatment, needs) and attitudes towards dementia care. The Interviews were conducted face-to-face from February 2020 to March 2020 in the Bengali language because 71% (Table 1) had language barriers.

2.2 SAMPLING AND SELECTION

We did not have the lists of all Bangladeshi-senior caregivers living in Toronto, so it was purposive sampling. The interviewers contacted seniors using the senior register list and informed them about the study and its purposes over the phone. The interviewers wanted to know from the possible participants about the nature of care for spouses/ family members/ friends as a caregiver. The study set three criteria, such as a. the participants perceived themselves as a caregiver for family members, relatives, and friends, b. the participants provided seniors with medication assistance, help for daily activities like cooking or preparing meals, making the bed for the seniors, and medical escort support to go to the health care system, and c. and the participants were able to provide information. Eighty-eight seniors met the criteria out of 310 from the registered list. However, 55 family caregivers agreed to participate in the survey. The participants originated from Bangladesh, and they migrated to Canada with family members, such as sons and daughters.

2.3 TRAINING, QUESTIONNAIRE, AND DATA COLLECTION

Four students from social backgrounds engaged in data collection. They were called interviewers. The interviewers participated in a two-day training at the BCS office, and the principal investigator (PI) conducted the training. The training included the rapport build-up with caregivers, interview techniques, explanations, and role play. The data collection process had three parts in the study: a. a small group discussion consisting of five caregivers to generate questions about dementia and attitudes towards care, b. the pre-test, and c. the final interview. In the pre-test survey, another five caregivers participated in the surveys. It helped the interviewers understand the responses or answers got from the caregivers and check inconsistency in the caregiver's information before finalizing the questions for the final interviews. Then the PI read the caregiver's responses meticulously after the pre-test, talked to interviewers when any clarification was needed, and modified the questionnaires for the final interview. **As ten caregivers out of 55 already participated in generating questions for the survey and participated in the pre-test survey, the rest 45 senior caregivers participated in the final interviews or surveys.** The interviewers invited the participants for a face-to-face interview at the BCS office. They completed the interviews during February-March 2020 before lockdown started in Ontario due to the COVID-19.

The study questionnaire included structured questions for socio-demographic characteristics information of the caregivers and semi-structured questions for understanding the

awareness about dementia and attitudes towards dementia care (given below). The interviewers used an audio/tape recorder while interviewing the participants, transcribed the narrations from the audio recording, and translated them into English. The individual interview took 30 to 45 minutes. After completing each interview, the PI immediately checked any information missing or inconsistency in their answers and consulted the interviewers for further action if needed. In addition, we re-interviewed 15 percentages of past interviews to check any discrepancy with previous interviews.

Survey questions:

1. Socio-demographic information (age, gender, school, ...sources of income).
2. What do you know about dementia and the symptoms and risk factors of dementia?
3. How do we prevent dementia, and what is the treatment of dementia?
4. How can dementia affect one's life?
5. How can you manage the person living with dementia?
6. What is your attitude toward the person living with dementia?
7. How do you help support the person living with dementia?

2.4 ANALYSIS

Two students received special training in the thematic analysis [22]. They had read the participant's answers repeatedly to get familiar with the meaning of answers and their implications. Thematic analysis followed six stages like a. familiarization with the information, b. generating initial codes, c. searching for themes, d. reviewing themes, e. defining and naming themes, and f. producing the report. The principal investigator checked the codes and themes to identify the accuracy and validity. The whole process did manually. Also, we applied descriptive analysis (just frequency).

3. RESULTS

3.1 SOCIODEMOGRAPHIC CHARECTERISTICS

In the study, the male and female caregiver ratio was 40% (18) and 60% (27), respectively (Table 1). The age range was between 55-72 years. Three-fourth of caregivers (77.8%, 35) completed 10-grade and more school educations, and they (68.9%, 31) lived in Canada for more than ten years. A great majority (71.0%, 32) had an English language barrier. The financial support was from government sources (60.0%, 27), followed by family support (40.0%, 18). About 42 caregivers (> 90%) had chronic diseases. The health information sources were workshops (75.6%, 34), followed by electronic sources (16, 35.6%), print media (26.7%, 12), and health professionals (16%, 7).

Table 1. Socio-demographic characteristics of family caregivers >55 years (N=45)

Socio-demographic characteristics	n (%)
Sex	
Male	18 (40.0)
Female	27 (60.0)
Education	
Completed ≥ 10 grades	35 (77.8)
Completed < 10 grades	10 (22.2)
Age	
55-59 years	8 (17.8)

≥ 60 years	37 (82.2)
Living in Canada	
< 10 years	14 (31.1)
≥ 10 years	31 (68.9)
Perceived language barrier	
Yes	32 (71.1)
No	13 (28.9)
Financial supports	
Government ^a	27 (60.0)
Family	18 (40.0)
Have Chronic diseases ^b	
Yes	41 (91.1)
No	4 (8.9)
Health information sources	
Health workshops	34 (75.6)
Electronic media ^c	16 (35.6)
Print media ^d	12 (26.7)
Health institution (doctor/hospital)	7 (15.6)

^a pension, benefit and support program, ^b diabetes, high pressure, high cholesterol, ^c electronic media= television / YouTube / websites, ^d print media= news paper/magazine/book

3.2 GENERAL AWARENESS OF DEMENTIA

Many caregivers (93.3%, 42) described that dementia as the disease of memory loss and forgetfulness (Table 2). The common symptoms of dementia were forgetfulness about the personal belongings where they put them (44.2%, 22), forgetfulness about the name and face of known persons, forgetfulness about the home locations (26.7%, 12), and forgetfulness of recent behaviors (15.5%, 7) (Table 2).

A male caregiver, 63 years, said,

“Immediate after eating food, the person living with dementia often forgets it and asks for food again and again.”

Furthermore, many caregivers (55.6%, 25) indicated that the person with dementia forgot to take medication, take a bath, and change clothing (55.6%, 25). Some caregivers said that the persons moved around when they lost their way to come home (22.2%, 10) (Table 2).

A female caregiver, 61 years, said,

“My husband has dementia. When he gets the chance, he goes out. He cannot come home, and he forgets how to return home, so he moves around.”

Regarding the risk, half of the caregivers (51.1%, 23) said that anxiety and depressions were the risk factors for dementia.

A woman caregiver, 64 years, said,

“When ones have anxiety and depression, the brain does not work properly, so one forgets even a small thing. It is dementia.”

Furthermore, many caregivers (48.8%, 22) said older age was another risk factor for dementia (Table 2).

A female caregiver, 62 years, said,

“As we are aging, our brain cannot work properly. Thus, forgetfulness is common after 60 years.”

Genetics (20%, 9), loneliness (15.5%, 7), chronic diseases (6, 13.3%), injury to brain cells (15.5%, 7), poverty (11.1%, 5), and poor nutrition (11.1%, 5) were also mentioned as risk factors (Table 2).

Table 2. Awareness of family caregivers (> 55 years) about dementia, symptoms, and risk (N=45)

Themes	Subthemes	Codes	n (%)	
	Dementia definition	Forgetfulness and memory loss	42 (93.3)	
	Symptom		45 (100.0)	
Awareness of dementia	Awareness of dementia	Forgetfulness about		
		-putting glasses, pen somewhere	22 (44.2)	
		-familiar person's name and face	12 (26.7)	
		-home locations	12 (26.7)	
		-recent behaviors	7 (15.5)	
		-taking medication / wearing dresses/ bathing	25 (55.6)	
		Move around	10 (22.2)	
		Awareness of risks		38 (84.4)
		Natural risk		
		-older age	22 (48.8)	
		-hereditary	9 (20.0)	
		Health risk		
-brain injury	7 (15.5)			
-chronic disease	6 (13.3)			
-anxiety and depression	23 (51.1)			
Socioeconomic risk				
-loneliness	7 (15.5)			
-poverty	5 (11.1)			
-poor nutrition	5 (11.1)			

3.3 AWARENESS OF PREVENTION AND TREATMENT OF DEMENTIA

A great majority of caregivers (51.1%, 23) were not aware of any preventive measures (table 3). The rest caregivers said that socialization, stress or anxiety-free life, engagement in daily activities, and medical advice could prevent dementia (49.9%, 22). Furthermore, many of them had no awareness about the ways of halting the progress of dementia. However, every two in five caregivers (42.2%, 19) reported that counseling, family support, medical advice,

and religious faith could prevent further progress of dementia. A great majority of caregivers (55.6.4%, 25) did not know the diagnosis providers and treatment providers (Table 3).

A female caregiver, 59 years, said,

"I went to the family physician with my sister because she forgets what she cooks. She forgets the name of her son. She is restless, and she cannot sleep at night. Her family physician did not say anything after listening to us about her problem. The doctor did not refer her to a specialized doctor. We are confused about where to go."

Some caregivers (40%,18) preferred to go to the family physicians because they (35.6%, 16) had no option except family physicians for identifying and treating dementia. Again, many caregivers (57.8%, 26) did not believe in drug treatment against dementia (Table 3).

A male caregiver, 67 years, said,

"This is useless to go to a doctor because there are no medicines to treat forgetfulness (dementia). No one can prevent memory loss, which happens at older ages."

The higher number of senior caregivers (86.6%, 39) did not know the benefit of non-pharmacological approaches (recreational activities) to improve the quality of life of the persons living with dementia (Table 3).

One female caregiver, 64 years, said,

"Nobody tells me that recreational activities could help the person living with dementia improve the brain function."

3.4 WHAT NEEDS FOR DEMENTIA CARE

One-fourth of caregivers (26.7%, 12) reported that they did not know about their needs for care towards the person living with dementia.

One female caregiver, 61 years, said,

"The persons living with dementia forget when they eat, and they cannot remember where they put their belongings. It is the natural phenomena at the older age. I do not know what I need to support them."

However, a greater proportion of the caregivers (42.2%, 19) needed close supervision for helping daily activities of persons living with dementia (Table 3).

A male caregiver, 65, said,

"The person living with dementia goes here and there. They cannot come back home. They can be lost. We have to keep eyes on them."

Only one-fourth of caregivers (24.4%, 11) needed adequate knowledge for dementia care towards the family members living dementia (Table 3).

A female caregiver, 61 years, said,

" I need to read about dementia care. We can know better by reading books."

Furthermore, many caregivers (46.6%, 21) needed classroom training for a better understanding of dementia and to provide care. One-fifth (20%, 9) needed close mixing with the persons living with dementia to learn about dementia care (Table 3).

A female caregiver, 55 years, said,

"If I mix with the person living with dementia, I can learn the requirements of them practically."

Table 3. Awareness of family caregivers (>55 years) about prevention, treatment, and needs for dementia care (N=45)

Theme	Subthemes	Codes	n (%)
Awareness of Prevention, treatment, and needs	Prevention	No awareness	23 (51.1)
		Have awareness ^a	22 (49.9)
	Providers	No ideas	25 (55.6)
		Family physicians	18 (40.0)
		Alzheimer's Society	6 (13.4)
	Treatment	No drug treatment	26 (57.8)
		No awareness about non-pharmacological treatment ^b	39 (86.6)
	Delay in progress	Have awareness ^c	19 (42.2)
	Needs of caregivers for dementia care	No knowledge	12 (26.7)
		Close-supervision ^d	19 (42.2)
		Complete knowledge	11 (24.4)
		Class room training	21 (46.6)
		Interaction with demented persons to learn	9 (20.0)

^aways of prevention: socialization, free from stress/anxiety, deep engagement in activities, doctor's advice, and brain work, ^brecreational activities like music, physical activities, crafting, etc (non-pharmacological approach) to improve the quality of life through community services, ^ccounselling, family support, doctor's advice, religion faith, ^dsupervision: movement, daily activities,

3.5 ATTITUDE TOWARDS DEMENTIA CARE

Many caregivers (84.4%, 38) were not afraid of dementia (Table 4).

One female caregiver, 63 years, said,

"It is not dangerous because no one dies of dementia, and most people are forgetful when dementia affects them."

A higher number of caregivers (44.4%. 20) reported that they would sympathize with a person living with dementia because they could not remember the past. However, many caregivers (55.6%, 25) thought that dementia was shameful for the person living with dementia and for the caregivers.

A male caregiver, 65 years, said,

"When my sister sees my brother-in-law, she calls him my father or her son. I feel shy, and I correct her. My brother-in-law becomes angry at her. We cannot go outside with her, and it disturbs the family life."

Furthermore, the caregivers (24.4%, 11) reported that persons living with dementia often forgot, and people called them mad and foolish. Half of the caregivers (51.1%, 23) would not go for dementia diagnosis if they had risks or symptoms of dementia (Table 4). Again, many caregivers (48.8%, 22) would hide their dementia from neighbors because the neighbors would disclose the information in the community. One-third (35.6%, 16) would hide dementia from both family and neighbors as it was embarrassing when people laughed at persons living with dementia. However, many caregivers would seek help from family members if they needed dementia care.

The interviewers asked the caregivers about the way of engagement in dementia care. Two-third of caregivers (68.8%, 31) would only teach the community people and the family members about dementia. A few caregivers (15.5%, 7) said that they would accompany the person living with dementia to the healthcare system (doctor, hospital). However, many caregivers (77.8%, 35) would not be caregivers for persons living with dementia.

A female caregiver, 61 years, said,

"I need to take care of myself and my husband. I do not want to take more burdens on my shoulders if my husband has a forgetfulness problem."

Table 4. Attitudes of family caregivers towards person living with dementia and dementia care (N=45)

Theme	Subthemes	Codes	n (%)
	Towards dementia		
		Dementia is not a dangerous disease	38 (84.4)
		Dementia is shameful	25 (55.6)
		They are mad and foolish	11 (24.4)
		Caregivers should be kind and helpful	22 (44.4)
Attitudes towards	Towards dementia diagnosis		

dementia care	Caregivers would not go for dementia diagnosis	23 (51.1)
	Towards hiding caregiver's dementia from	
	Community	22 (48.8)
	Family and community	16 (35.6)
	No tendency to hide	7 (15.6)
	Attitudes in dementia care	
	Caregivers would only teach people about dementia	31 (68.8)
	They would not be a caregiver for dementia care	35 (77.8)
	Caregivers would go to healthcare system with them	7 (15.5)

4. DISCUSSION

The study explored the awareness of the South Asian Bangladeshi family caregivers (> 55 years) about the symptoms, risk factors, preventive measures, treatment, and attitudes towards dementia care. The caregivers had low awareness about dementia, symptoms, risk factors, and preventive measures. Again, the awareness about the benefit of pharmacological care (drug treatment) and non-pharmacological care (recreational activities) was limited. Dementia was associated with shame, and the caregivers would hide dementia from their surroundings. Many caregivers would not engage in dementia care. Poor knowledge, stigma, and less interest in dementia care for the persons living with dementia can affect the diagnosis and the quality of life of the person living with dementia in the South Asian Bangladeshi family. The study findings and its implication are described below.

The caregivers described dementia as forgetfulness and loss of memory due to older age in the study. The concept of dementia is more than the caregiver's perception [23-25]. The studies in China, Cuba, and India found a similar poor perception about dementia [26-28]. Furthermore, the study caregivers had incomplete knowledge about symptoms of dementia. It can delay early diagnosis and management [29]. It is urgent to create awareness among Bangladeshi Canadian family caregivers before dementia gets the worst in the family. High cholesterol, blood pressure, diabetes, vascular diseases, depression, genetics, obesity, and habitual smoking are significant risk factors for dementia [30-36].

However, the study caregivers reported anxiety and depression, and older age as the main risk factors for dementia. The awareness of risk factors among caregivers in China is better than that of the study caregivers [37]. The low level of knowledge about the risk factors will not help the caregivers to prevent family members and themselves from dementia. In addition, the caregivers perceived that dementia was an unpreventable disease. Similar findings were seen across the world [38,39]. However, physical exercise, brain activities could prevent dementia [40]. Education about risk and protective factors is crucial for the Bangladeshi community living in Canada to tackle dementia in the future.

Furthermore, the caregivers did not believe in the pharmacological treatment of dementia, so they were not aware of the medical benefits of drug treatment. China got similar findings [26]. Non-pharmacological approaches (like recreational activities), such as music, physical and meaningful activities that are brain-stimulating, could promote the quality of life of the

person living with dementia [41-43]. The study caregivers were also not aware of the benefit of non-pharmacological care or recreational activities for persons living with dementia. The local community centers could provide the caregivers with the scope to learn about the benefits by engaging them in recreational activities.

The family caregivers perceived dementia as shameful in the study, a common perception worldwide [44,26]. For this, the study caregivers would hide their dementia from the family members. Again, the study explored that caregivers did not want to engage in dementia care for persons living with dementia. Limited awareness about dementia care and fear of shame associated with dementia could be reasons. These could delay effective dementia care in the family. Research is required about how to engage caregivers in dementia care. Moreover, social workers and health professionals can make dialogue, conferences, and workshops to engage caregivers in caring for persons living with dementia.

The study has limitations. It included a convenient sampling based on the availability of caregivers. The findings cannot be generalized for the national population, but the results could relate to other South Asian ethnicities because of the same cultures or cultural similarities. Thus, the policymakers could get new information for taking initiatives for the South Asian caregivers. The study included qualitative research because of the small sample size as we did not have a complete list of caregivers living in Toronto, funding, and resources for quantitative studies. However, qualitative research could explain the in-depth perception of dementia [21]. In those cases, 45 caregivers and their explanations towards dementia and its care were good enough to understand the context. We could not apply different methods for triangulation because of time, shortage of resources, and no funding for the study. We set the guidelines to maintain the quality of the study at different levels, such as training for interviewers, data collection, record-keeping system, re-interview. Though we have limitations, however these findings of the study help plan effective interventions.

4. CONCLUSION

In conclusion, dementia is a public health concern in Canada, and we have the National Dementia Strategies for better care; however, the South Asian Bangladeshi family caregivers (>55 years) in Canada had limited knowledge about dementia. Also, the stigma existed in the caregivers, and they were not much interested in caring for the persons living with dementia. These all affect the quality of care for persons living with dementia in South Asian Bangladeshi families. Effective implementation of the National Dementia Strategies in South Asian families, initiatives of grassroots organizations for dementia awareness programs, funding for research, and community supports could increase caregivers' awareness, reduce stigma, and increase caregivers' involvement in dementia care.

CONSENT

Before starting the interview with the participants, the interviewers read the purpose, objectives of the study, and way of maintaining confidentiality to the participants. The interviewers also informed the participants that we used the collected information for the publication, and we did not use the participant's name anywhere else. If participants needed clarification, the PI would address their concerns. If participants agreed to provide the information, the interviewers invited the participants to give us the written consent. We developed a standard consent form to sign. We applied the face-to-face interview and used audio-record while interviewing.

ETHICAL APPROVAL AND ISSUES

The internal ethical board of BCS went through the proposal for ethical issues and approved the study. There was no medical investigation on the participants or any clinical trial, so we did not require rigorous ethical considerations. The participants gave us written consent for a verbal interview. Also, we followed the Helsinki Declaration of Ethical Principles for Human Subjects and maintained confidentiality strictly. The participants agreed to participate, and then the interviewer started interviewing. The participant's answers or narrations were anonymous. The participants had the right to refuse to answer any question, to stop giving information at any point of the interviews. They were not bound to return. We did not use any person's name in the study. The participants had the right to know the findings for their clarification. The interviewers kept information in a separate area, so only the principal investigator accessed the information.

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