



## RESEARCH ARTICLE

# Strategies adopted by informal carers to enhance participation in daily activities for persons with dementia

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## Abstract

**Objective:** Carers for people with dementia commonly experience difficulty assisting the care-recipients with their daily activities and may adopt specific strategies to decrease the difficulties experienced. The objective of this qualitative study was to explore and understand the strategies used by carers to assist with daily activities for persons living with dementia.

**Methods:** Individual semi-structured interviews via face-to-face or telephone mode were conducted with 62 carers of persons living with dementia in Australia. Carers were asked about the strategies they have used previously, or are currently using, to assist with daily activity completion. Data were analysed via constant comparison and thematic analysis.

**Results:** All carers reported the need for strategies to accommodate the varying behaviour and functioning of the care-recipients. Participants reported a total of 207 strategies that fell into four main categories: (i) engage; (ii) adapt; (iii) orientate; and (iv) sense. The most used strategies were reported as those aimed at adapting the activity by using equipment to facilitate completion.

**Conclusions:** Carers help persons living with dementia complete their daily activities by developing their own strategies based on the care-recipients' needs and personal preferences through a trial-and-error process. Carers can benefit if more advice is provided to them by health/social care professionals regarding what strategies may be helpful. Further studies are needed to develop these strategies into an educational package so that carers can be guided to use these strategies appropriately.

## KEYWORDS

caregiver stress, education, family caregivers

Gemma Burridge and Carmen Amato are co-first authors.

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## 1 | INTRODUCTION

Dementia is a highly prevalent condition, with approximately 70% of people with dementia residing in the community.<sup>1</sup> An estimated 92% of this population receives care from one or more carers.<sup>2</sup> The Australian Institute of Health and Welfare<sup>2</sup> describes the term ‘carer’ as loosely referring to someone who provides ongoing informal assistance to a person living in the community who is unable to care for themselves independently. Three main reasons have been identified for why a person decides to commit to the role of caregiving. They are as follows: (1) the wish to keep the family member at home; (2) closeness to the person with dementia; and (3) the carer’s perceived obligation as a spouse, partner or child.<sup>3</sup> In a prevalence study conducted in the UK, more than 70% of dementia carers were aged over 65, with close to 17% aged above 80 and about 70% being female.<sup>4</sup>

Those providing care to people with dementia encounter many difficulties. Carers must provide increasing assistance with everyday activities, manage behavioural disturbances and adapt to the decreasing ability to communicate with the care-recipient as their independence diminishes.<sup>5</sup> This leads to an increased risk of the carer experiencing role strain, depressive symptoms, burn-out, financial and employment hardship and burden.<sup>3,6</sup> Therefore, it is essential to support informal carers in providing care for the benefit of both the carers and the persons with dementia.

Carer education has been shown to relieve the general caring burden.<sup>7</sup> Most strategies or methods described in the literature are aimed at promoting the psychological well-being of carers, such as counselling or developing coping skills. Few studies focus on specifically educating carers on how to assist with everyday activities, and few studies identify everyday caregiving strategies carers use when assisting people with dementia in their daily activities.<sup>7</sup> Carers new to dementia caregiving or facing new challenges in caring will require practical advice and strategies to manage their care-recipient’s daily activities.<sup>8</sup> A collection of the strategies used by experienced carers would be helpful to assist carers in developing strategies to maintain or enable daily activity participation for care-recipients with dementia. However, there are no available resources that offer a comprehensive list of strategies for providing care in daily activities for dementia carers.

Therefore, the objective of this study was to explore and understand the strategies used by carers to assist with daily activities for persons living with dementia. The useful strategies collected will provide a resource that health professionals may draw upon.

### Practice Impact

Strategies described in the literature are usually aimed at promoting the psychological well-being of carers. This study collected over 200 useful strategies used by experienced dementia carers to assist care-recipients in completing and participating in everyday activities. The strategies collected enable the creation of a valuable resource for other carers.

## 2 | METHODS

### 2.1 | Study design

This study was part of a multi-phase research project that aimed to improve the services for people with dementia and their carers by exploring, developing, implementing and evaluating the most effective strategies carers use when assisting people living with dementia to complete their daily activities and to help with challenging behaviours. It expands on our previous work investigating the assistance provided in daily activities and the difficulties experienced by carers of people living with dementia.<sup>6</sup> This qualitative study reports the valuable strategies used by dementia carers that were captured through individual interviews. This approach enabled an in-depth analysis of the strategies carers used when assisting a person living with dementia with daily activities.

Ethics approval was obtained from Western Sydney University (H11758) and the South Western Sydney Local Health District Human Rights Ethics Committee (HREC project number: HE16/050).

### 2.2 | Participants

The overall study consisted of two linked participant groups: people with dementia and their carers. This paper presents the carers’ perspective. People with dementia were the care-recipients, and although not active participants in this phase of the study, their demographic and background data are presented to provide greater context to the qualitative results.

All participants were recruited from an aged care unit in a large metropolitan teaching hospital in New South Wales, Australia. Carers of patients in the aged care unit with a diagnosis of dementia received written and verbal information regarding the study. Purposive sampling was used to recruit participants who met the selection criteria. Carer-care-recipient dyads were included if they

met the following criteria: (1) the care-recipient had been diagnosed with dementia by a geriatrician; (2) the carers were aged 18 years and above, did not report having any cognitive impairment and assumed primary responsibility for the care-recipient; and (3) the care took place in a home or independent living setting. Carer-care-recipient dyads were excluded if the care-recipient had other medical conditions that required assistance in daily activities, such as a previous spinal cord injury.

Carer-care-recipient dyads provided informed consent prior to participating in all phases of the study.

## 2.3 | Data collection

After consent was obtained, medical information and demographic characteristics were gathered from the medical records of the recruited care-recipients with dementia.

Semi-structured interviews took place with recruited carers via face-to-face meetings in a private room in the hospital, free from distractions or over the phone. Interpreters were available if needed. Interviews lasted for approximately 30 min.

Interviews were structured via a predesigned semi-structured interview guide/survey in which carers were asked open-ended questions about the methods they had used or were currently using during a typical day and were useful in helping the care-recipient complete their daily activities. The predesigned survey included the following two sections:

1. demographic data of the carer and
2. strategies or methods employed by carers when assisting in daily activities and managing challenging behaviours exhibited by their care-recipients

Daily activities include self-care activities of daily living (ADLs), instrumental activities of daily living (IADLs), leisure activities and other related activities. Verbatim quotes were recorded during the interview via handwritten notes on the survey papers. The accuracy of these notes was checked by interviewers with participants as each interview progressed to ensure caregiving strategies were correctly documented pertaining to the various activities of daily living discussed. Verbatim quotes were typed up following interviews and entered into an Excel spreadsheet for each participant.

## 2.4 | Data analysis

Data analyses commenced at the time of data collection. A constant comparative method was employed for analysis and involved continuously comparing and

categorising the emerging themes from the data.<sup>9</sup> This was completed through a line-by-line analysis of all interviews, with each unit of information assigned a code, a process known as open coding.<sup>10</sup> Each unit of coded data was then analysed and compared to other coded data through axial coding to determine key relationships between categories.<sup>9</sup> The central phenomenon was developed through selective coding to identify the core theme of the dataset.<sup>10</sup> This process enabled the data set to be reduced to the main categories that characterise the strategies carers use when providing care to a person living with dementia.

## 3 | RESULTS

### 3.1 | Participants

Sixty-seven carer-care-recipient dyads were eligible to participate in the study. Five carers had withdrawn from the study because of unavailability after their care-recipients were discharged from the hospital. Interviews were conducted in English with a final sample of 62 carers, providing a response rate of 93% in this qualitative phase of the study. All recruited carers spoke and understood English. No interpreter was required. [Table 1](#) reports the baseline information of the care-recipients and carers.

### 3.2 | Strategies reported

A total of 207 strategies were reported by carers, with an average of nine strategies per carer. All participants reported implementing strategies through a trial-and-error process. All carers acknowledged that strategies need to be flexible as the care-recipient's needs, preferences, and behaviour can vary significantly from day to day and within the same day.

The constant comparative method employed for analysis revealed an overarching core phenomenon of 'managing daily life to promote ease of caregiving and meaning for care-recipients'. This core phenomenon revealed that carers individualised their approach to providing care by incorporating a range of flexible and innovative strategies to encourage care-recipients' participation into daily care, reduce agitation and confusion, and prevent behavioural challenges that might result. In addition, strategies utilised by carers were carefully trialled and selected to be meaningful to care-recipients at a personal level. With trial-and-error, the carers developed an individualised way of supporting their care-recipients to be cooperative and engaged in a meaningful way in the daily caregiving activities required. Four categories

TABLE 1 Background information of care-recipients and carers.

	Care-recipients ( <i>n</i> = 62)	Carers ( <i>n</i> = 62)
Age, mean (SD)	83.19 (8.24)	62.02 (14.87)
Gender, <i>n</i> (%)		
Female	31 (50)	44 (71)
Male	31 (50)	18 (29)
Years of formal education, mean (SD)	7.47 (4.46)	9.43 (5.88)
Living alone, <i>n</i> (%)	6 (10)	
Living with spouse/partner, <i>n</i> (%)	21 (34)	
Living with family/children, <i>n</i> (%)	35 (57)	
Type of dementia, <i>n</i> (%)		
Alzheimer's type	21 (34)	
Vascular	11 (18)	
Frontotemporal	3 (5)	
Lewy body	4 (7)	
Mixed	11 (18)	
Unknown	12 (19)	
Rowland Universal Dementia Assessment Scale <sup>a</sup> , mean (SD)	18.30 (6.40)	
Employment, <i>n</i> (%)		
Paid employment		15 (24)
Student		2 (3)
Retired, unemployed or no paid employment		45 (73)
Relation to care-recipient, <i>n</i> (%)		
Wife		10 (16)
Husband		7 (11)
Children		38 (61)
Other		7 (11)
Living with care-recipient, <i>n</i> (%)		53 (86)
Months living with care-recipient, mean (SD)		363.64 (261.84)
Months providing care, mean (SD)		75.36 (68.50)
Daily hours providing care, mean (SD)		19.11 (8.03)

<sup>a</sup>The Rowland Universal Dementia Assessment Scale is a multicultural cognitive assessment scale. It is scored out of 30, with scores below 23 suggesting dementia.

outline the key strategies used by carers known to be successful in these participants' dementia caregiving. They are as follows: 'engage', 'adapt', 'orientate' and 'sense'. There were 13 subcategories within these categories (Figure 1A,B, Appendix S1). 'Adapt' had the most reported strategies (46%), followed by 'orientate' (26%).

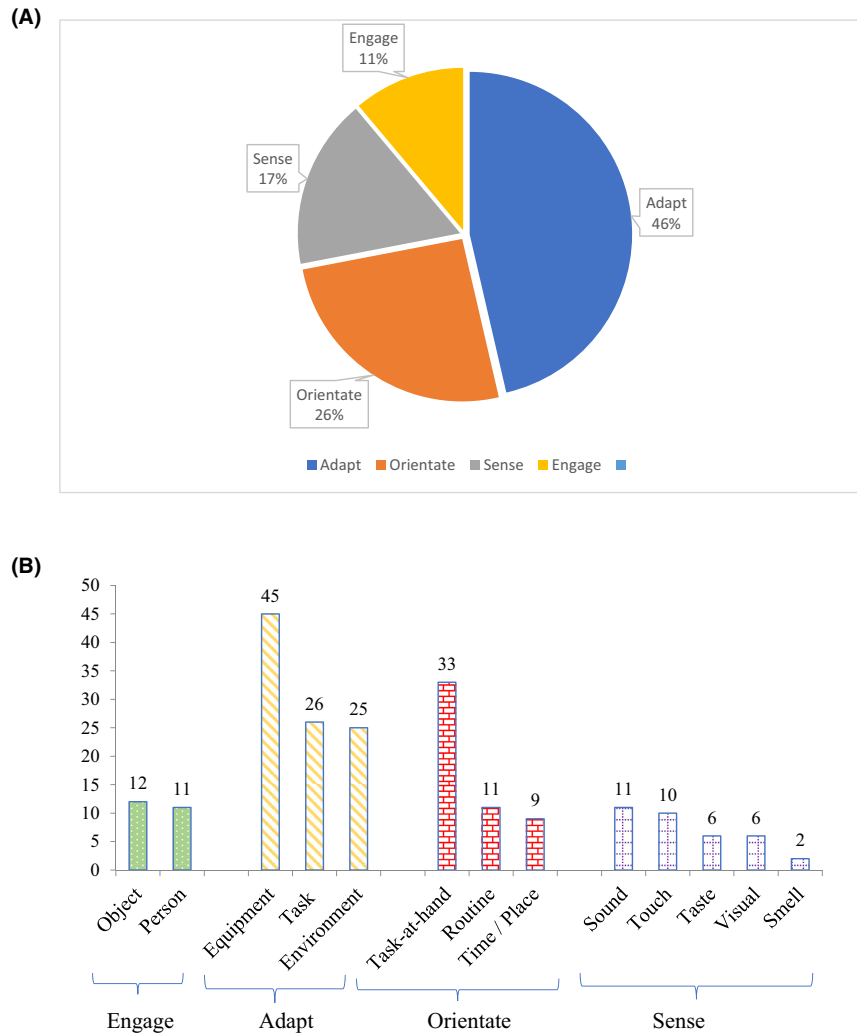
### 3.2.1 | Category 1—Engage

Engagement is an approach to daily caregiving that includes strategies to increase the care-recipient's interest in different activities. It consists of two sub-categories—'engagement through person' and 'engagement through object'. 'Engagement through person' involves human

interactions with carers. Examples included completing daily activities together, such as brushing hair simultaneously. Being surrounded by familiar people can reduce the care-recipient's confusion and agitation. 'Engagement through object' used interactions with objects to increase engagement. For example, encouraging care-recipients to engage with dressing by using their favourite clothes or reviewing photographs of loved ones, which can decrease agitation and encourage conversations.

### 3.2.2 | Category 2—Adapt

Adaptation includes strategies to adapt daily tasks to enhance care-recipient involvement. Three sub-categories



**FIGURE 1** (A) Percentage of carers who reported useful strategies in each category. (B) Number of reported useful strategies in each category and sub-category. The y-axis indicates the number of strategies reported for each sub-category.

include adapting either the ‘task’, ‘equipment’ or ‘environment’ to promote activity performance by care-recipients. All strategies within this category included some form of adaptation to ease any challenging aspects of tasks. These strategies varied daily, sometimes requiring more or less adaptation. Carers reported this to be dependent on the functional status of the care-recipients. Many carers reported more adaptation being required in the late afternoons due to behavioural changes associated with sundowning. All carers in this study reported that more task and equipment adaptation is required over time as the functionality of the care-recipients diminishes secondary to the progressive nature of dementia.

‘Adapting the task’ involves altering the order, process or steps of the activity. This includes breaking down the task into smaller steps to make it easier for the care-recipients. Crushing medication into food was commonly reported to aid medication management. Other strategies reported include using a shopping list to remind about

needed items, and preparing meals in advance and freezing them to make meal preparation easier.

‘Adapting the equipment’ or ‘using adaptive equipment’ is where carers change the equipment used (e.g., using smaller spoons, or contrasting colours for plates and cutlery) or use specialised equipment (e.g., shower chairs, bedside rails and electronic recliner chairs). This sub-category had the most strategies reported. Using pull-up underpants was useful for incontinence management and a hospital bed helped carers with transfers. Wheelchairs, recliner chairs, bed sticks, slide sheets, handheld showerheads and stairlifts are other examples of equipment.

‘Adapting the environment’ is where carers change the surrounding physical or social environment. Environmental strategies used by carers ranged from putting signage around the house, labelling items, having friends and family to help with tasks, receiving help from paid carers, locking doors, living on lower floors, hiding

keys, disconnecting the stove, providing set-up assistance for showering, hiding items in the kitchen and staying in warm temperatures. One carer described having a chair in the kitchen so that the care-recipient could feel included during meal preparation, which reduced confusion and agitation.

### 3.2.3 | Category 3—Orientate

Carers reported using specific strategies to orientate care-recipients to daily activities. There were three sub-categories falling under 'orientate', including orientating care-recipients to the current 'time' or 'place', establishing 'routine' to structure the entire day or week, and orientating to the 'task at hand', which involved bringing the attention of care-recipients to the current task. Carers reported that care-recipients were more compliant with performing the task at hand if they were oriented in the present. Many carers also reported that care-recipients could rest with more ease when there were items encouraging orientation in their surroundings.

Strategies in the 'time/place' sub-category specifically orientate the care-recipients to the current time and place. Examples of these strategies included using a large digital clock and calendars, and sitting by the backyard pond as that was a familiar place for the person. Another carer described always keeping the care-recipient home at night to prevent confusion and agitation.

Strategies involving 'routine' were helpful for carers in orientating the care-recipients. Sticking to a certain routine or maintaining consistency helped prevent the care-recipients from becoming flustered and agitated. It was also a useful method to help carers organise their time. One carer encouraged their care-recipient to eat as much as possible earlier in the day when their appetite was at its peak. Carers reported it was essential that this routine be flexible to adapt to the fluctuations of functioning and mood variations.

'Task at hand' strategies included preparing care-recipients before engaging in tasks. An example is to inform them of the task before beginning. Carers noted that avoiding any distractions by not conversing with care-recipients during activities could help with task progression. During the task performance, carers spoke about providing verbal prompts to make the task easier for the care-recipients. Prompting could include giving instructions using third-person language or using favourite items of the care-recipients to prompt cooperation, for example, one carer reported showing the care-recipients their

favourite shoes to prompt them to get out of bed in the mornings.

### 3.2.4 | Category 4—Sense

Carers identified strategies that aimed to change the sensory input for the care-recipient. This strategy uses the five senses (sight, hearing, touch, smell, and taste) to create strategies while caregiving. Carers identified that people living with dementia experienced changes in how they perceived sensory information, which could impede their ability to regulate sensory perception. Therefore, carers regulated the sensory environment as a strategy to enable participation in daily activities. Strategies within this theme were always aimed at reducing agitation and promoting calmness by soothing the care-recipients.

A 'visual' strategy described by a carer was to remove all the mirrors in the home as they caused the care-recipient to become confused and agitated. Other visual strategies involved providing appropriate lighting during activities and keeping the blinds shut to improve sleep.

'Sound' strategies included listening to music and audiobooks to promote relaxation.

A 'touch' strategy reported by a carer involved maintaining hot water contact with the care-recipient during showering to increase their compliance and comfort. Another carer described stroking the care-recipient's hair during the night to comfort and reduce agitation. For care-recipients familiar with knitting or sewing, the activities were another 'touch' strategy for enjoyment.

Strategies involving 'taste' included drinking tea for relaxation, eating soft foods to improve appetite and reduce problems associated with swallowing, taste testing foods and taking medications with sweet drinks or food.

## 4 | DISCUSSION

The study explored the strategies used by carers in providing daily activities care for people living with dementia. A total of 207 strategies to ease the provision of care were reported. Analysis of the strategies used by carer participants provides a range of useful strategies that can enhance participation in daily activities of people with dementia, thus enabling the creation of a valuable resource for other carers. The core phenomenon that emerged from all carers' experiences showed that carers assist care-recipients in managing daily life and promote ease in the caring process and meaningfulness for the care-recipients.

Most strategies reported in the current literature are administered by health professionals or aimed at

preserving the general well-being and mental health of the carers, rather than presenting methods or tips to relieve the effort of caring.<sup>3,5,7,11</sup> With the progressive nature of dementia affecting people's daily life, assisting with daily activities is considered the prominent role of any carer.<sup>3,6</sup> Despite this, in a primary care setting, less than half of dementia carers receive advice from professionals regarding strategies to manage the progression of dementia with specific targeted outcomes such as enhancing participation in daily activities.<sup>5,7,11</sup> This was reflected in the current study, where nearly all carers stated that the strategies were their 'own idea' developed from their experience of caring rather than from any other sources.

Implementing strategies that aim to engage the care-recipients in daily activities is highly beneficial for the carers and care-recipients.<sup>11</sup> Less strain is placed on the carers if the care-recipients complete or receive assistance to complete their daily activities without much struggle. Strategies to engage care-recipients in any form benefit the care-recipients as completion of daily activities encourages a sense of purposefulness and is physically and cognitively stimulating.<sup>12</sup>

The 'adapt' strategies involved the adaptation of tasks, equipment and environment to promote the completion of daily activities. Carers commonly reported effective strategies consistent with the communication strategies reported by Wilson et al.<sup>12</sup> when assisting individuals with moderate to severe dementia during the successful completion of daily activities. 'Equipment' adaptation was the largest sub-category under 'adapt'. Carers described using specialist equipment to assist those with deterioration in physical capacity. In the 'environment' sub-category, carers reported adaptations of the home environment in particular. Carers described arranging items, signage, labels, locks and hiding or disconnecting dangerous items. This complements the current literature regarding environmental adaptations to support successful ageing in their homes and communities.<sup>13</sup>

In keeping with the 'orientate' category, some carers reported using calendars to orientate their loved ones, which is supported by Evans and Collier,<sup>14</sup> who describe the effective use of calendars to support time orientation and maintain routines. Verbal and visual prompting were common strategies that carers described when helping care-recipients complete daily tasks. This is consistent with the previous literature supporting the use of prompting<sup>15</sup> and communication strategies<sup>11</sup> for people with dementia. New technologies are being developed to use a prompting tool to facilitate completing multi-step daily activities.<sup>16</sup> A consistent routine was another strategy that carers used to orientate the care-recipients, although

current resources refer to routine mostly in terms of helping carers to organise their time and reducing boredom for the person with dementia.<sup>3</sup>

The strategies described by carers that fell under the 'sense' category were all aimed at soothing the care-recipients through the use of sensory input. These strategies were consistent with the principles of sensory-based interventions, which are well-described in the literature involving the use of multi-sensory interventions to counteract sensory deprivation that may cause problematic behaviours.<sup>17</sup> A study by Bauer et al.<sup>18</sup> suggested that multi-sensory interventions effectively relax people with dementia. However, the interventions reported in the study were administered by staff in nursing homes rather than informal carers. Another study by Trueland<sup>19</sup> supported using a sensory approach in nursing homes to soothe care-recipients, which could increase engagement in daily activities. Our study has shown that informal carers are already using some of these sensory strategies, and therefore may benefit from further education on administering a more extensive range of sensory techniques.

The strategies identified may help to reduce the carer burden and promote care-recipient independence. The strategies are always individualised according to the care-recipients' needs. The process that carers undertake to get the strategies right is a dynamic and ever-changing process for carers and is directly informed by in-depth knowledge of the care-recipient's likes, dislikes and the approaches that are most meaningful for the care-recipients.

#### 4.1 | Strengths, limitations and future direction

This study identified a range of useful strategies from the carers' perspectives. It provides good resources that health professionals can draw upon. The findings are specific to the 62 participants who took part in the study, and there may be variation in different groups of dementia carers. A description of the carer-care-recipient demographic will provide a context to the findings to allow others to explore whether the strategies identified by these carers are relevant to other settings and contexts. Some strategies might have been reported as effective for some carers and counterproductive for other carers. Therefore, the strategies described in this study may not be applicable to every person with dementia. Carers may have to engage in trial-and-error to find the most suitable strategies for caring for their loved ones. Carers may also require guidance in selecting strategies suitable to their care-recipients and specific circumstances.

Further knowledge of the strategies that carers can use to ease care provision is essential. Identification of which carer-care-recipient dyads benefit from specific strategies and/or guided use of the strategies with the involvement of a health-care professional may be of value in implementing these useful strategies. Furthermore, the challenges that carers of people with dementia face daily need to be fully understood so that meaningful and effective interventions may be developed.

## 5 | CONCLUSIONS

All carers reported strategies or methods useful for them to ease the provision of care for the person with dementia. These strategies fall into four main categories: 'engage', 'adapt', 'orientate' and 'sense'. Among all strategies, 'adapt' was the most reported, particularly adapting daily activities with equipment. Carers expressed that it was essential to select the appropriate strategy according to the care-recipients' behaviour and functioning. Therefore, further studies are needed to develop these strategies into an educational package so that carers can be guided to use these strategies appropriately.

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## CONFLICT OF INTEREST STATEMENT

No conflicts of interest declared.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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