Nurses’ Experiences of Caring for Long-Term Care Residents With Dementia During the COVID-19 Pandemic

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Abstract
The COVID-19 pandemic has had a negative impact on older persons who reside in long-term care settings, especially residents living with dementia. The physical and psychological burden of the current pandemic has also been felt by frontline caring staff including nurses caring for persons living with dementia. The aim of the study was to explore the experiences of nurses while caring for residents with dementia who resided in long-term dementia care units during the COVID-19 pandemic. Nine Maltese nurses working in dementia care units were interviewed during the month of February 2021. Following analysis of the transcripts, three themes were identified; ‘living the challenges of the pandemic’, ‘passing through a roller coaster of emotions’ and ‘building on personal and organisational resilience’. The participants lived through several challenges which in turn generated both positive and negative emotions. Moving forward through this period mostly relied on their coping strategies, how they negotiated infection control measures with the residents’ quality of life and how their organisation was able to provide quality dementia care pre-COVID-19. The study indicated how personal and organisational resilience could have influenced the participants’ experience of the pandemic and helped nursing staff in developing new ways of working.

Keywords
COVID-19, dementia, dementia units, long-term care, nurses, qualitative

Introduction
The coronavirus disease 2019 (COVID-19) pandemic we are currently experiencing is having a profound effect on frail older adults, especially those residing in long-term care institutions. The spreading of the severe acute respiratory syndrome associated with SARS-CoV-2 virus that leads to the disease has impacted heavily on older adults with over 95% of the associated deaths occurring in persons over the age of 60 years (World Health Organization, 2020). Moreover, the average share of deaths in residential homes across the world accounted to 46% of all deaths (Comas-Herrera et al., 2020). In Malta, the impact of COVID-19 on older adults changed considerably between one pandemic wave and another. During the first wave (between March and July 2020), the cumulative case fatality ratio of older adults was significantly lower than in other countries (Cuschieri & Grech, 2021). This was particularly due to the total lockdown and social isolation measures in residential and nursing homes (Fenech et al., 2020). However, once these measures were relaxed in the summer of 2020, the mortality rate of older persons increased exponentially in the second half of 2020 (the second wave), with 91% of the deaths due to...
COVID-19 consisting of older persons, especially those living in residential homes. It was only in January 2021, when older adults were prioritised to be administered the COVID-19 vaccine and eventually given the booster doses, that deaths due to COVID-19 started to decrease, becoming one of the lowest in Europe (European Centre for Disease Prevention and Control, 2021).

Similar to older adults, the COVID-19 pandemic had a significant negative effect on the physical and mental wellbeing of persons living with dementia and their family members (Wang et al., 2020). Not only did persons living with dementia have a higher risk of death (Suárez-González et al., 2020), they are more likely to exhibit behavioural and psychological symptoms of dementia (BPSD), especially in long-term care settings. These can be exacerbated as a result of the impending infection, lack of social engagement by the family members due to restrictions on gatherings, disruption in non-pharmacological group interventions, barriers in maintaining person-centred care and communication by frontline staff (Keng et al., 2020).

In Malta, there are an estimated seven thousand persons living with dementia, with this figure expected to double within the next twenty years (Scerri & Scerri, 2012). Prior to the pandemic, the Maltese government and private organisations have sought to improve the provision of dementia care in the community and for residents living in long-term care. The publication of the National Strategy for Dementia in the Maltese Islands (Scerri, 2015), has spearheaded these initiatives. However, the challenges and restrictions imposed by the pandemic significantly affected the management of the current services and the development of new ones. Consequently, there is an urgent need to explore and describe how the provision of dementia care in Malta has been impacted by the pandemic.

The toil of the current pandemic is also being felt by frontline staff. It is being predicted that nurses working in nursing homes will have the highest COVID-19 mortality rate amongst frontline workers (McGilton et al., 2020). Residential home staff are also at an increased risk of experiencing guilty feelings associated with the loss of residents they have been caring for (Greenberg et al., 2020). These negative emotions could also be accentuated by the ethical dilemmas that nurses have to face and the stigma of being perceived by the public as ‘disease carriers’ (Maben & Bridges, 2020). These challenges indicate the need for psychological support to care home staff during these times (Bolt et al., 2020).

While there is initial evidence of the living experience of care home staff during the pandemic, most of the current evidence is anecdotal and requires more rigours studies. Moreover, in view of the challenges associated with caring for persons living with dementia as highlighted above, the experiences of staff working in dementia care units during the COVID-19 pandemic, could be considerably different from that of other frontline workers. Therefore, the aim of this study was to explore the experiences of nurses while caring for residents with dementia who resided in long-term dementia care units during the COVID-19 pandemic. The objectives of the study were to explore how nurses provided nursing care in dementia units during the pandemic; what were the challenges they faced and how they overcame these challenges. This information would enable a better understanding of how to support nursing staff working with residents living with dementia during these hard times and identify recommendations to improve the quality of care in these settings, post-COVID-19.

**Methods**

**Study Participants**

The targeted population consisted of all staff nurses working in six dementia units in a large public funded long-term care institution in Malta of around 1400 beds. Whilst the majority of the persons living with dementia in Malta are supported by family members (Innes et al., 2011), a minority live in nursing homes; some of whom in specialised dementia units. Dementia units consist of units usually found in nursing homes that have similar characteristics like trained staff and a modified physical environment, that provide a safe home and care to persons living with dementia, especially those exhibiting significant behavioural symptoms (Lai et al., 2009). The majority of the nursing staff manning these wards were general nurses who were specifically trained to work with persons living with dementia. The selected participants had to be full-time staff nurses or charge nurses who have been working for at least 1 year (during the COVID time period) in these dementia units.

**Ethical Approval**

Ethical approval was sought and granted by the senior management and data protection officer of the nursing home and by the University Research and Ethics Committee. Moreover, participants were given referral to psychological support if this was needed during the session. Pseudonyms were used when referring to the nurses to maintain their anonymity.

**Data Collection**

Online one-to-one interviews using the video-telephony software program Zoom (Zoom Video Communications, San Jose, California) were held with nine nurses working in dementia units in a long-term care facility in Malta using an interview schedule consisting of semi-structured questions (Table 1). All interviews lasted approximately an hour and were transcribed verbatim. The majority of interviews (except of two held in Maltese) were held in English during the month of February 2021, during which time Malta was going through the third wave of the pandemic.

Full-time staff nurses ($n=43$) working in six dementia units were contacted during the month of January 2021 by an intermediary who sent the information letter together with the
consent form by email to all qualified nurses working in dementia units. Initially 10 nurses responded to the call to participate in the study. However, one of the participants decided not to participate without giving any further reasons. Thus, nine nurses (six females and three males), who fell within the inclusion criteria, consented to participate and were purposively selected. All of the nurses who consented to participate have been working in the dementia units at the start of the pandemic in March 2020 with an average number of years working in dementia wards of approximately 4 years. Moreover, six of the participants were charge nurses in their respective wards. All six wards were represented by at least one staff.

**Data Analysis**

Giorgi’s steps of collecting verbal data, reading the data, breaking the data into parts, organising the data into meaningful subthemes and synthesising them into themes, were used (Giorgi, 1997) (Figure 1). To achieve an overall understanding, all transcribed interviews were first read by AS to make sense of the whole without any presumed assumptions. Each transcript was then re-read and distinct units of meaning were identified and organised into subthemes. Once the subthemes were generated, these were further organised into themes. NVivo 12 (QSR, international, 2018) was used to aid in coding and organising the identified subthemes.

**Reflexivity and Personal Assumptions**

A reflective diary that included the researchers’ reflections of the findings was kept throughout the research study. Since the COVID-19 pandemic has affected the researchers’ lives personally, attempts were made for the researchers’ individual experiences, not to influence the findings. As a result, they

| Table 1. Interview schedule. |
|-------------------------------|
| **How long have you been working with residents with dementia?** |
| **What type of residents with dementia do you have in the wards you work in?** |
| **How are you providing nursing care during the COVID-19 pandemic?** |
| Prompts: Managing challenging behaviours? Communicating to family members? Coping with mitigation measures? |
| **What are the daily challenges you face during the COVID-19 pandemic?** |
| Prompts: How do you cope? |
| Prompts: How do you go about overcoming these daily challenges? |
| Prompts: How do you feel? |
| Can you describe a duty? |
| Prompts: Morning or day duty? A night duty? Christmas and holiday season? |
| How are you working when compared to pre-COVID-19 time? |
| Prompts: How much is it similar? How much is it different? |
| **How do you think will this experience of the COVID-19 pandemic influence the way you care for residents with dementia post-COVID-19?** |
| Prompts: In terms of the way you feel toward persons living with dementia? In terms of the way you communicate with them? In terms of the way you communicate with family members? |

![Figure 1. Giorgi’s steps as used in the data analysis of the study.](image-url)
remained vigilant on these assumptions throughout the research study. This was sought by 'bracketing' their own assumptions through an attitude of critical reflection (Chan et al., 2013). Using this approach ensured that the themes were grounded on the participants’ experiences of living during the pandemic and not the researchers’ presumed assumptions.

Results

Three main themes were identified: ‘living through the challenges of the pandemic’, ‘passing through a roller coaster of emotions’ and ‘building on personal and organisational resilience’. The units of meaning, the subthemes and main themes are described in Table 2.

| Table 2. Units of meaning, subthemes and main themes as developed using Giorgi’s steps of data analysis. |
|---|---|---|
| Breaking the data into units of meaning | Organising the units of meaning into related subthemes | Organising related subthemes into main themes |
| • Use of personal protective equipment | Challenges related to maintaining infection control measures and COVID-19 testing | Living the challenges of the pandemic |
| • Swabbing of self and residents | | |
| • Stopping/restricting family visits | | |
| • Restrictions in mobility by residents | Challenges related to residents | |
| • Physical and cognitive deterioration by residents | | Organisational challenges |
| • Communicating with residents | | |
| • Disruption in daily routines | | |
| • Increasing workload and lack of staff | | |
| • Limiting resident activities | | |
| • Worse than a prison like a bird in a cage living in another world it is like sort of war | Seeing the challenges through the eyes of the residents | |
| • Fear | Negative emotional turmoil | Passing through a roller coaster of emotions |
| • Anxiety and stress | | |
| • Anger | | |
| • Sadness | | |
| • Moral distress | | |
| • Empathy toward residents and relatives | Positive emotions | |
| • Increased job satisfaction | | |
| • Increased sense of duty and responsibility | | |
| • Spiritual coping | Personal coping strategies | Building on personal and organisational resilience |
| • Physical activity | | |
| • Family support | | |
| • Hobbies | | |
| • Meaning-focused coping | | |
| Peer support | | |
| • Effective leadership | Organisational resilience | |
| • A dementia-friendly environment | | |
| • Open organisational culture | | |
| • Use of technology | | |
| • Good relations with relatives | | |

Living the Challenges of the Pandemic

Challenges Related to Maintaining Infection Control Measures and COVID-19 Testing. All participants faced similar challenges at work during the pandemic. Some of these challenges were related to infection control measures that had to be introduced as part of the mitigation measures in order to reduce the spread of the virus. The use of personal protective equipment, especially the mask and the visor, over a long period of time was ‘uncomfortable’ and sometimes ‘suffocating’, especially during the hot summer days. Nevertheless, participants were concerned when they noticed that these measures were not being followed by other staff members and found it particularly frustrating in ensuring that all staff abide by the infection control policies.
Let me tell you something. It’s a policy that every member and every staff should wear a visor and a mask. It’s a policy! (Thelma)

The use of protective equipment was perceived by some of the staff of ‘robbing’ them with the possibility of providing adequate person-centred dementia care, especially in terms of providing effective communication with their residents. For example, the use of gloves was referred to feeling ‘fake’ and a barrier for maintaining physical contact. Moreover, masks were perceived as impeding non-verbal communication through facial expressions and eye contact, especially for persons who are hard of hearing.

Regular and repeated polymerase chain reaction test (PCR) COVID-19 swab testing of residents and themselves was also perceived to be quite challenging. It was very difficult to explain the procedure to some residents, who found it particularly distressing. Keeping residents calm during swabbing was perceived by participants as ‘difficult’, ‘a big hassle’ and a ‘hard task’ to perform, sometimes requiring physical restraints. Some participants questioned whether these repeated swabs for the residents and for themselves were really necessary.

The fact that we are taking many swabs … it is not very nice. For example, we are taking it every 15 days, but where my wife works, since it is a closed ward, I feel it is exaggerated, they are doing it every 3 days. (Mark)

**Challenges Related to Residents.** Participants expressed the difficulty to explain to the residents why they could not get out of their room, especially when their unit became under quarantine or when residents became COVID-19 positive. According to the participants, these restrictions increased challenging behaviours, especially agitation and aggression. While some nurses acknowledged the residents’ frustration and sought to reassure them, other participants were disappointed that they could not provide adequate communication and support due to the isolation measures.

They are locked. They cannot go out…. They don’t communicate between each other; they do not engage in conversation between themselves. They feel isolated and it kills. From my experience, isolation kills! (Marthese)

Isolation not only increased non-cognitive symptoms but participants observed residents to have deteriorated in their general condition after being transferred back to their own units from the ‘COVID ward’. Participants felt ‘frustrated’, ‘painful’ and ‘hurt’ at how their residents deteriorated, especially in their mobility.

When you see a patient, who used to walk from early morning to the evening, she tires you walking. Now it is tiring seeing her sitting down. It is painful for us seeing her like that. (Mark)

**Organisational Challenges.** The residents’ physical deterioration significantly disrupted the participants’ daily routines and increased staff workload with the ward becoming ‘heavier’ since residents required more physical attention. Participants were seeing other staff complaining that they required more workforce to provide for the physical needs of their residents. Moreover, their ‘modus operandi’ changed significantly due to the social distancing measures, with a decrease in the input of allied healthcare professionals and activity organisers. Staff felt that the lack of organised activities, especially outdoor activities, was particularly missed by some of the residents.

Stopping or restricting residents from seeing their family members paid a heavy toll not only on the residents, but also on the staff who used to rely on their input, especially to support the residents’ engagement, mobilisation and feeding.

When the relatives were here, they used to walk them around and taking them for a walk. But now it is lacking. (Marthese)

The use of technology through the use of online chats with the relatives and restricted family visits ‘from behind the Perspex’ has helped in maintaining contact with their family members, for some of the residents. However, these initiatives were not always perceived as effective for all residents. According to participants, some of the residents, especially those with moderate to severe dementia, were unable to reap the benefits of these technologies.

With regard to organising face-to-face family visits, once these were permitted, some participants observed ‘heart breaking’ family meetings that touched them deeply. However, they also referred to residents who became increasingly agitated because they could not understand why they were not allowed to make physical contact with their family members. Nevertheless, there was a general feeling that the restrictive family visits during the pandemic could have also improved the mood and behaviour of some of the residents. They referred to occasions before the pandemic whereby residents used to become more agitated or more distracted during family visits, especially during mealtimes.

**Seeing the Challenges Through the Eyes to the Residents.** All of these challenges and the changes brought about by the pandemic was viewed by a number of participants from the perspective of their residents. This was evident through the use of metaphors in describing what they thought their residents were experiencing. The participants’ acknowledged the surreal world that the residents might be experiencing, especially when they saw them wearing the personal protective equipment.

The patients (are) looking at you as if we came from ‘Mars’. At first, they are afraid. One patient started laughing and said, ‘Come on, why are you hiding your face, you fool?’ (Barbara)
The type of interaction between the staff and the residents imposed by the pandemic was also metaphorically described by one participant as like ‘feeding a bird in a cage’. Similarly, the swabbing of patients was perceived by another participant as ‘like a war’ since it led to significant agitation.

**Passing Through a Roller Coaster of Emotions**

**Negative Emotional Turmoil.** The challenges referred to by the participants have instilled a number of emotions. These were related to the risk of getting infected or having their loved ones getting infected, the stress at the place of work associated with the increased workload, as well as emotions such as frustration, anger and sadness on observing their residents deteriorating.

At home I have a one-year-old baby, so I am always asking myself that I can be (COVID) positive, because there were staff here that became positive as well. Even though you take all the precautions. (Bertha)

Although participants were afraid of contracting the infection and spreading it to their loved ones, one participant was angry that some staff were not providing the appropriate care and engaging in activities with their residents for fear of getting infected. Her emotional turmoil was associated with moral distress of not being able ‘to be a nurse’ in the current circumstances and the difficulty in negotiating mitigation measures with the resident’s quality of life.

Everybody is more anxious, everyone has his own problems, everyone has his family and are afraid to take COVID (infection) home...However, we are nurses, no? (Marthese)

A sense of helplessness and sadness pervaded when nurses talked about the way their residents deteriorated after they were transferred back from the ‘COVID ward’. They referred to this moral distress as a ‘double-edged sword’ when they were trying to understand why residents deteriorated during the time they spent in quarantine in the ‘COVID ward’.

The change in dependency level of the residents, together with restricted family visits, also increased stress at work with the staff finding it increasingly hard to cope. According to one participant, the stress at work has led to an increase in sick leave.

Staff have certain stress. I notice from the sick leave and I noticed that they do not give them vacation leave. (Victor)

**Positive Emotions.** While all participants expressed negative emotions, positive emotions arising from their experiences were also reported. Some nurses became aware of the need to be ‘more respectful and responsible for each other, while others became more empathic toward their residents and the relatives.

But what changed my mentality is that these residents used to have their family visiting them. They had someone. Once that stopped, we the health care workers were the only people for them. And it made me realise that I can, I should have more empathy. That is the thing. That I have to always remember that as a healthcare worker, I am the one for them, especially if they don’t have relatives coming in. (Tania)

Moreover, the use of technology during the pandemic has also helped in building ‘better relationships with the relatives’ and generated a feeling of satisfaction that they are somehow reducing the distress of the residents or relatives caused by the social distancing measures.

To be honest, I am not obliged to do it on my own personal mobile, but I do it with pleasure. (Victor)

**Building on Personal and Organisational Resilience**

**Personal Coping Strategies.** The participants’ experience was varied, depending on whether or not the unit was quarantined and whether the residents got infected and subsequently transferred to another ward. Moreover, the participants’ experiences were also dependent on their personal coping strategies and how they came into terms with the pandemic. Apart from one participant who indicated that her smoking habit increased, all participants referred to adaptive coping strategies such as spiritual coping, physical activity, hobbies, family support and ‘a quiet time’.

Researcher: How did you use to cope. Naturally, when you go home you take the problems home.

Robert: Yes, but I used to remain quiet for half-an-hour and listen to music.

One of the respondents (Tania) felt that she kept herself motivated by reminding herself of her sense of duty toward the residents in her unit. She preferred to sacrifice her free duties and work overtime to avoid relievers working in her ward, thus minimising the risk of the residents in her care getting infected.

**Organisational Resilience.** Participants identified a number of organisational characteristics that significantly influenced the pandemic experience. Peer support and effective teamwork was perceived to be important in reducing the anxieties caused by the pandemic and ensuring that the residents who deteriorated would be rehabilitated back to their previous selves.

Robert was frustrated that the physical environment of the dementia unit he works in, was not designed in a dementia-friendly way. This limited the possibility to organise activities indoors that could have been maintained during the
pandemic. Similarly, the absence of a suitable outdoor space was considered by two participants as having a significant impact on the way the pandemic was experienced, especially by the residents.

Other participants criticised the lack of flexibility of the senior leadership in changing the staffing levels once the residents’ dependency level changed. They felt that the senior management did not respect them enough and did not always listen to their concerns. This made them demotivated and increased their emotional distress. Since most of the staff found it hard to work during these stressful times, they felt they would have benefitted if psychological support was provided.

While these organisational characteristics negatively influenced the way the participants coped during the pandemic, there were genuine attempts set by the organisation or by the participants themselves to maintain some form of ‘normality’. Participants described, how the infrastructure was adapted (e.g. WIFI connectivity and availability of electronic tablets) to maintain contact between the relatives and the residents and between staff and relatives. All participants agreed that such technology should remain post-COVID-19.

For example, I have a patient (in my care). I had to call her son every night, because she did not want to stay. So, the fact that she used to see him and he used to tell her ‘Listen mum, it’s okay you can stay with them’. It’s amazing. I mean, it helps a lot. The tablet helped. It was a very good idea. (Tania)

Organisational resilience was also evident by the fact that participants continued to organise activities, which although limited, maintained some form of engagement.

We tried our best to decorate the rooms and the dining room and everything, even now we have decorations of Valentine’s and Carnival, so that we make a better atmosphere. (Bertha)

Discussion

The participants in the study identified a number of challenges related to infection control measures, such as in the use of personal protective equipment, swabbing of patients and stopping or restricting family visits. Nyashanu et al. (2020) also identified similar challenges experienced by frontline workers in health and social care in the United Kingdom, including difficulties in enforcing social distancing, anxiety and fear, and staff shortages. However, noticeable differences are apparent between these two studies. For example, unlike the current study, in Nyashanu et al. (2020) study, participants perceived the shortage of personal protective equipment as being a significant challenge. The reason for this difference could be due to the fact that the Nyashanu and colleagues’ study was conducted at the initial phase of the pandemic when health and social care systems across the world were still adapting to the spread of the disease.

Studies carried out in long-term care settings in the third and fourth quarter of 2020, showed similar adverse outcomes to residents, as identified in this study, such as the physical de-conditioning. Lombardo et al. (2020) observed an increase in the use of psychotropic drugs and use of restraints in Italian nursing homes with the authors arguing that such occurrence was attributed to mitigation measures that were taken to contain the spread of infection in these settings. The restrictions in family visits in long-term care settings during the pandemic could have contributed to behavioural eating disorders and poor feeding in long-term care settings (Shum et al., 2020).

The negative emotional turmoil highlighted in this study was also expressed by healthcare professionals in studies conducted elsewhere. Ardebili et al. (2021), found that healthcare providers in Iran experienced similar negative emotions such as anxiety, fear and increased level of stress. Moreover, similar studies have referred to the moral distress expressed by some participants, who felt powerless and were finding it difficult to come into terms with the restrictions imposed by the pandemic. Bolt et al. (2020) acknowledged the need to raise awareness about the grief experience and moral distress of nursing staff. As indicated by one of the participants in this study, nurses working in dementia units require psychological support to come into terms with these emotions. Likewise, the need for psychological and peer support for frontline staff has been repeatedly mentioned in the literature (Maben & Bridges, 2020). Nevertheless, the participants in this study utilised adaptive personal coping strategies such as engaging in physical activity or hobbies to enhance their mental well-being. This psychological resilience of frontline workers has also been seen elsewhere (Aughterson et al., 2021). Moreover, the current study showed that thinking positively about life events could have helped the participants’ psychological well-being. Similarly, maintaining positive emotions have also been related to psychological resilience of healthcare professionals during the COVID-19 pandemic (Bozdağ & Ergün, 2020).

The findings of the study indicated how organisational resilience could have influenced the participants’ experience of the pandemic. The provision of the video chat service to maintain communication between the residents and their relatives is an example of how the organisation responded to the lockdown. Participants felt that although not all residents benefited from this initiative, it reduced the residents’ behavioural symptoms and facilitated regular communication between the staff and the relatives. Similarly, Padala et al. (2020) reported how Facetime™ helped in improving quarantine-induced behavioural problems in a resident with Alzheimer’s disease. Participants felt that the application of technology in this regard should continue following the pandemic. This has also been highlighted in a report aimed at describing the impact of the COVID-19 pandemic on dementia well-being (Liu et al., 2021).

Participants identified additional organisational characteristics that influenced the quality of care provided to their
residents. Dementia-friendly designs that include adequate outer space have been considered as lacking in some units. According to the nurses interviewed, the lack of investment in such design’s features negatively affected the residents’ well-being, especially during quarantine. This was further exacerbated by the staff shortage, lack of leadership support and clear guidelines. Similarly, Iaboni et al. (2020) argued that in order to provide safe, and compassionate quarantine, nursing homes need to invest in adequate resources and leadership support. It can be argued that a person-centred approach to dementia care (Brooker & Latham, 2015) has become increasingly more important than before the emergence of the COVID-19 pandemic. On the other hand, the current study has shown that ‘new ways of working’ (Ni Shé et al., 2020) can be developed to continue providing effective dementia care.

**Strengths and Limitations**

A descriptive phenomenological approach enabled the portrayal of the participant’s experience, without being altered through the preconceived ideas of the researchers. Since the experiences are context specific, the generated themes cannot be generalised to other dementia units abroad. However, some of the findings resonate the experiences of nurses in similar studies (Catania et al., 2021).

**Conclusion**

Further research is needed to understand how the COVID-19 pandemic has impacted persons with dementia and their formal and informal caregivers. The lessons learned from the pandemic experience can help nurses and managers working in dementia units, developing strategies aimed at improving the services provided to persons with dementia, post-COVID-19.

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