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Provision of Palliative Care for Patients with Advanced Dementia across Various Long-Term Care Settings in Japan: A Questionnaire-Based Survey

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Abstract: Long-term care (LTC) settings are increasingly used for palliative care in Japan. This study aimed to assess the proportion of LTC settings that provide palliative care services for older clients with advanced dementia in Japan and the trends across the types of settings. A nationwide questionnaire survey was conducted between November 2022 and January 2023, targeting 1,000 geriatric hospitals (GHs), 1,000 geriatric health services facilities (GHSFs), and 1,000 home nursing care stations (HNCSs). The palliative care practices for older patients with advanced dementia and their families in the agencies were assessed. Less than half of the GHs supported family participation or the spiritual needs of their older clients with dementia, while many had access to pain and symptom assessments and analgesic prescriptions by physicians. Less than half the GHSFs used pain assessment tools, assessed and supported family caregivers' pain and distress, and supported family participation in palliative care. More than 80% of the HNCSs practiced most of the listed palliative care. Current palliative care practices for older adults with dementia vary among GHs, GHSFs, and HNCSs. This emphasizes the need for targeted approaches to improve the provision of palliative care for patients with dementia across LTC settings in Japan.

Keywords: dementia; long-term care facility; home nursing care; family involvement; palliative care; spiritual care

1. Introduction

Long-term care (LTC) is defined as health and supportive care services provided to people with chronic illnesses or disabilities who cannot care for themselves for long periods, usually over months or years [1]. It includes various care services, such as personal care, social services, room and board, transportation, and medical and rehabilitative care [1,2]. A mandatory LTC insurance system was launched in Japan in 2000 to meet the increasing demand for care for older individuals with disabilities [3,4]. This system is based on the concept of a patient-centered social insurance system that supports independence [4]. LTC insurance implementation requires a nationally standardized needs certification system to objectively determine service eligibility [3,4]. Patients enrolled in this service submit a standardized questionnaire on activities of daily living and a report from their physician to a local committee. This committee determines the beneficiary's level of need and the corresponding quantity of services provided [4]. Patients with certification for this service can utilize facility-, home-, and community-based services, depending on their physical and cognitive impairments as determined by their care manager [5]. LTC insurance beneficiaries can choose between care managers and science parks. LTC facility services are provided in many settings in Japan, including geriatric hospitals (GHs), geriatric health service facilities, nursing homes, group homes, and personal residences [4]. These facilities are sponsored by for-profit or non-profit companies.

Population aging has led to an increase in the proportion of older individuals, creating a public health challenge. Because mortality is inevitable in an aging population, the place of death is of great concern to healthcare policymakers and service providers [6,7]. For older individuals, LTC settings are increasingly used for palliative care [8,9]. This is because older individuals generally prefer to die in their homes or LTC facilities surrounded by their families, relatives, friends, and familiar staff [10]. Since an essential indicator of good palliative care is the death of a patient at their preferred place of death [11], older adults may choose to stay in their own houses or LTC facilities until death. This may limit their activities of daily living and reduce their access to hospital care [12].

The Japanese LTC insurance system includes three categories of LTC facilities: GHs, GHSFs, and nursing homes. GHs are hospitals dedicated to caring for older patients with disabilities or chronic diseases who require medical management, nursing care, and rehabilitation services. They differ from typical adult hospitals because they can implement palliative approaches, which makes them sustainable with improved quality-of-life outcomes. GHSFs are intermediate facilities between GHs and nursing homes that provide institutional care such as medical, rehabilitation, and nursing care services. They also offer respite care services for older individuals living at home. HNCSs are nursing stations for recuperative care or medical assistance provided in the individual's home. They provide 24-hour telephone consultations and visiting home care ranging from preventive to palliative care. Visiting nursing home care is supported financially by both the LTC and public medical insurance systems. As they approach the end of life and require high-intensity palliative care, patients with a physician order can use medical insurance for frequent visits.

However, Japan has a low proportion of in-home or facility deaths compared to Western countries such as Canada, the UK, and the US (Taniguchi et al. [13]; National Vital Statistics System, 2020). From a policy perspective, it is essential to understand how to bridge the gap between people's wishes and reality at the end of their lives in LTC settings. To address this issue, the discrepancy between LTC insurance services and beneficiaries' palliative care needs should be resolved. Thus, studies related to palliative care provision and its details across LTC settings can provide a better understanding of palliative care development in Japanese LTC settings. Research on palliative care provision in LTC settings can provide insight into the development, effectiveness, and real-world practicality of palliative care. Many previous studies have suggested that the diseases of institutionalized older patients remain underdiagnosed and, thus, untreated or undertreated. Furthermore, higher levels of unmet care needs in LTC settings are associated with poorer quality of life in older patients [8,9,14,15]. Notably, older individuals with advanced dementia have multiple palliative care needs, including pain, eating problems, aspiration, pressure ulcers, behavioral and psychiatric symptoms of dementia (BPSD), burdensome transitions, and limited access to palliative care [16,17].

Despite research efforts and policy commitments to improve care for people with dementia who wish to die in their homes, there is a paucity of knowledge on the methods to achieve optimal palliative care in dementia [18,19]. A systematic review [18] showed the potential benefits of domiciliary palliative care interventions in improving end-of-life care outcomes, such as the management and reduction of behavioral disturbances in people with dementia.

However, more studies are needed to evaluate patients' expectations of palliative care when transferred to another setting, as this causes considerable challenges to the continuity of palliative care [20–22]. To guarantee good end-of-life quality in people with dementia, the change in palliative care content during transitions at the end of life should be investigated more thoroughly [23–25]. While some studies have crudely estimated the level of palliative care engagement in LTC settings [9,26–28], others have endeavored to adapt, implement, and evaluate multi-component palliative care educational programs for LTC settings [29–32]. This study aimed to assess the proportion of LTC settings that provide palliative care services for older clients with advanced dementia and whether there are distinctive trends across these settings.

2. Materials and Methods

This cross-sectional study involved a nationwide questionnaire survey conducted between November 2022 and January 2023. A self-administered questionnaire was mailed to 3,000 agencies: 1,000 GHs, 1,000 geriatric health services facilities (GHSFs), and 1,000 home nursing care stations (HNCSs). The agencies were selected using systematic sampling from 3,500 GHs, 3,566 GHSFs (two were excluded due to temporal closure), and 14,068 HNCSs via public national databases. The databases used were the Japan Medical Analysis Platform (https://jmap.jp/) for GHs, the directory of the Japan Association of Geriatric Health Services Facilities for GHSFs, and an open database managed by the Japanese Ministry of Health, Labour, and Welfare (https://www.mhlw.go.jp/stf/kaigo-kouhyou_opendata.html) for HNCSs. The head nurse at each agency, as designated by the agency director, participated in the study. As it was anonymous, a reminder was mailed to all 3,000 agencies after the nomination deadline of December 2022 to remind them to return the questionnaire.

2.1. Measures

2.1.1. Palliative care practices

The current palliative care practices for older patients with advanced dementia and their families in the agencies were assessed using an eight-item, four-point Likert scale survey (Yes, Rather Yes, Rather No, No). This survey covered the following items: 1) pain assessment; 2) multidisciplinary team meeting for total pain; 3) pain scale; 4) pain killer (including opioid) prescribed by a physician; 5) attention to spirituality; 6) pain and stress management for families; 7) family’s participation in palliative care; 8) multidisciplinary team meeting for BPSD. A qualitative methodology was employed to create an interview topic guide for the questionnaire survey. This enabled us to gain insight into the perception and attitude of healthcare professionals with dementia expertise regarding the current state of pain assessment and management in older adults with advanced dementia. The procedure was followed by an expert panel review by the research team members with dementia expertise who extracted items from the questionnaire.

A literature search was conducted, focusing on popular books pertaining to palliative care for older people with advanced dementia published in Japanese or translated from English to Japanese and available as of April 2021. The goal was to identify the specific components of each dimension of total pain: physical, psychological, social, and spiritual. Details are described elsewhere [33]. Subsequently, individual in-depth interviews were conducted between January and March 2022, using reference materials created based on the literature review findings. Participants were healthcare professionals with ample experience in primary palliative care for dementia, recruited through convenience sampling from the authors’ acquaintances (Table 1). The interviews, lasting 30–45 minutes, were conducted online, and the participants were asked to add their ideas and experiences.

Table 1. Characteristics of interview participants.

Participant No.	Profession	Specialty	Sex	Age range	City	Setting	Experience in dementia care (in years)	Other relevant information
1	Physician	Emergency medicine	Female	40–44	Tokyo	Home	Unknown	Home care physician with abundant clinical experience in emergency rooms

2	Physician	Geriatric medicine	Female	40–44	Tokyo	Hospital	8	University faculty member with abundant clinical experience in home care
3	Physician	Home care medicine	Male	40–44	Tokyo	Hospital	Unknown	Geriatrician with ample experience in hospital, facility, and home care
4	Physician	Palliative medicine	Male	55–59	Akita	Hospital	15	
5	Physician	Palliative medicine	Male	40–44	Miyagi	Hospital	10	University faculty member with ample experience in home care
6	Nurse	Palliative care/Geriatric care	Female	55–59	Hokkaido	Hospital	Unknown	Works at a geriatric hospital
7	Nurse	Geriatric care	Female	45–49	Hokkaido	Home	3	Works at a home-visit nursing station affiliated with a hospital
8	Nurse	None	Female	50–54	Morioka	Hospital	30	Is certified as a care manager and social worker and has experience in home-visit nursing care and community-based integrated care
9	Nurse	Palliative care	Female	50–54	Akita	Hospital	13	Works at an outpatient ward and room for community health
10	Nurse	Geriatric care	Female	55–59	Saitama	Home	25	Works at a home-visit nursing station affiliated with a group home for older people with dementia
11	Nurse	Geriatric care	Female	40–44	Aichi	Hospital	10	Works at a dementia care unit
12	Nurse	Dementia care	Female	40–44	Aichi	Hospital	8	Works at a dementia care unit
13	Nurse	Dementia care	Female	35–39	Aichi	Hospital	10	Works at a dementia care unit
14	Nurse	Dementia care/Geriatric care	Female	60–64	Hiroshima	Home	20	None
15	Nurse	Geriatric care	Female	40–44	Nagasaki	Hospital	20	Works at a room for community health
16	Physical therapist	None	Male	40–44	Miyagi	Home	6	None
17	Care manager	None	Female	45–49	Akita	Home	20	Chief care manager in charge of education
18	Care manager	None	Female	45–49	Miyagi	Home	15	Has work experience in long-term care facilities for older people with dementia
19	Care manager	Dementia care	Female	40–44	Miyagi	Home	18	Has five years of experience of working in a long-term care facility
20	Social worker	None	Female	60–64	Chiba	Home	10	Works at a community center
21	Social worker	None	Female	45–49	Nagano	Hospital	30	Works at a room for community health
22	Social worker	None	Female	40–44	Niigata	Home	10	Works at a home clinic providing palliative care
23	Social worker	None	Male	30–34	Gunma	Hospital	10	Works at a room for community health in a rehabilitation hospital

24	Social worker	None	Male	40–44	Kanagawa	Facility	10	Founder of small-scale long-term care facilities

The interview explored various topics, including assessment of the total pain of patients and their families, treatment methods (i.e., drip infusion, opioid use), and palliative care provision (i.e., symptom management, teamwork, support for family, communication, and interventions to improve patient-family relationships). Qualitative data from individual interviews were shared with the authors to gather additional ideas and opinions. The first author, a geriatrician with ample experience in qualitative research, conducted all interviews. Based on the interview results, the panel members utilized the Delphi technique to develop a consensus on relevant palliative care services to develop questionnaires [34]. Advanced dementia, for this study, was defined as a Functional Assessment Staging score of 6 or 7 [35].

2.1.2. . Background characteristics

The questionnaire also gathered background characteristics, including participant and agency details, administration, and educational systems. Participants' characteristics included age, sex, nursing experience, and facility ownership. Agency-related data included: 1) the year of establishment, 2) ownership, 3) the presence of other healthcare facilities in the same organization, 4) facility function (GHSFs only), 5) the number of full- or part-time nurses, 6) the ratio of registered nurses to assistant nurses, and 7) the number of clients per month. Administration-related information encompassed 1) certified nurse-specialist staffing (geriatrics, dementia, palliative care), 2) routine assessments (dementia care and palliative care), 3) online reception support, 4) community-based advance care planning support, 5) availability of planning forms, and 6) advisability of palliative care service till the end of life (GHSFs only). Educational systems data included: 1) dementia care, 2) assistance with eating, 3) oral care, 4) pressure ulcer prevention and management, 5) decision-making support, 6) advance care planning, and 7) palliative care (to the end of life).

3. Results

Out of 1,000 participants in each group, 100 (10%) GHs, 170 (17%) GHSFs, and 230 (23%) HNCSs responded. The respondents' characteristics are listed in Table 2. Many GHs and GHSFs were run by medical corporations as private, not-for-profit entities. HNCSs were recently established through small-scale private corporations. The GHs and GHSFs were likely to be affiliated with a hospital, whereas the HNCSs were likely to be affiliated with a designated home care support office. In such offices, a care manager provides older clients who require home care with home care planning and care coordination services. Although one-fourth of the GHs had one or more certified dementia nurse specialists, few provided education on both dementia and palliative care across all study settings. As for service availability, community-based advanced care planning (ACP) support services were not common across GHs, GHSFs, and HNCSs. However, two-thirds of the GHs and GHSFs utilized a standardized ACP format, and a quarter of the GHSFs had regressive policies toward palliative care service provision until death at their facilities.

Table 2. Characteristics of study settings.

		GHs (n=100)		GHSFs (n=170)		HNCSs (n=230)	
		n	%	n	%	n	%
Governing body	Medical cooperation	75	75.0	124	72.9	67	29.1
	Social walfare cooperation	3	3.0	22	12.9	12	5.2
	Incorporated association	8	8.0	10	5.9	17	7.4
	Private cooperation	0	0.0	0	0	102	44.3
	Others	14	14.0	13	7.6	23	10.0
Establishment	-1999	49	49.0	84	49.4	41	17.8

	2000-2009	12	12.0	29	17.1	23	10.0
	2010-2019	10	10.0	19	11.2	67	29.1
	2020-	1	1.0	0	0	19	8.3
Number of nurses	-9	3	3.0	25	14.7	169	73.5
	10-19	28	28.0	126	74.1	42	18.3
	20-49	27	27.0	11	6.5	2	0.9
	50-99	20	20.0	1	0.6	0	0.0
	100-	16	16.0	0	0.0	0	0.0
Affiliated institution	General hospital	42	42.0	76	44.7	52	22.6
	Clinic	10	10.0	31	18.2	25	10.9
	Home nursing care station	35	35.0	50	29.4	—	—
	Home care support office	41	41.0	111	65.3	117	50.9
Certified nurse specialist staffing	Geriatrics	2	2.0	1	0.6	1	0.4
	Dementia	25	25.0	5	2.9	3	1.3
	Palliative care	17	17.0	1	0.6	11	4.8
Education	Dementia care	21	21.0	24	14.1	23	10.0
	Palliative care	5	5.0	7	4.1	20	8.7
Service availability	Online reception support	72	72.0	133	78.2	19	8.3
	Community-based advance care planning support	19	19.0	22	12.9	42	18.3
	Advance care planning form	64	64.0	113	66.5	86	37.4
	Palliative care service to death (GHSFs only)	—	—	133	78.2	—	—

The palliative care practices at GHs, GHSFs, and HNCSs are shown in Table 3. Less than half of the GHs supported family participation in palliative care or provided spiritual support for their older clients with dementia. While many GHs had access to pain and symptom assessments and analgesic prescriptions by physicians, less than half the GHSFs used pain assessment tools in their facilities. Similarly, less than half of GHSFs assessed and supported family caregivers' pain and distress and supported family participation in palliative care for their clients. Except for multidisciplinary BPSD management conferences, more than 80% of the HNCs practiced all the listed palliative care practices: pain and symptom assessment in palliative care, multidisciplinary pain and symptom management discussions in palliative care, use of pain assessment tools, opioid and non-opioid analgesic prescriptions by physicians, spiritual support, assessment of and support for family caregivers' pain and distress, and family members’ participation in palliative care for patients with dementia. Only one-fourth of the HNCSs held multidisciplinary BPSD management conferences.

Table 3. Practices of palliative care from the perspectives of study settings.

		GHs (n=100)		GHSFs (n=170)		HNCSs (n=230)	
		n	%	n	%	n	%
Pain and symptom assessment in palliative care	Yes	31	31.0%	37	21.8%	133	57.8%
	Rather Yes	51	51.0%	78	45.9%	77	33.5%
	Rather No	10	10.0%	28	16.5%	9	3.9%
	No	7	7.0%	26	15.3%	7	3.0%
Multidiciplinary pain and symptom management discussion in palliative care	Yes	25	25.0%	38	22.4%	80	34.8%
	Rather Yes	40	40.0%	66	38.8%	105	45.7%
	Rather No	26	26.0%	37	21.8%	35	15.2%
	No	8	8.0%	27	15.9%	9	3.9%
Use of pain assessment tool	Yes	39	39.0%	10	5.9%	95	41.3%
	Rather Yes	32	32.0%	30	17.6%	93	40.4%

	Rather No	20	20.0%	59	34.7%	29	12.6%
	No	8	8.0%	71	41.8%	12	5.2%
Opioid and non-opioid analgesic prescribing by physician	Yes	69	69.0%	54	31.8%	137	59.6%
	Rather Yes	15	15.0%	32	18.8%	67	29.1%
	Rather No	7	7.0%	22	12.9%	12	5.2%
	No	8	8.0%	62	36.5%	14	6.1%
Spiritual support	Yes	12	12.0%	12	7.1%	76	33.0%
	Rather Yes	37	37.0%	34	20.0%	100	43.5%
	Rather No	34	34.0%	67	39.4%	39	17.0%
	No	16	16.0%	56	32.9%	15	6.5%
Assessment of and support for family caregivers' pain and distress	Yes	18	18.0%	21	12.4%	108	47.0%
	Rather Yes	41	41.0%	63	37.1%	94	40.9%
	Rather No	29	29.0%	54	31.8%	19	8.3%
	No	10	10.0%	31	18.2%	9	3.9%
Family member's participation in palliative care for patient with dementia	Yes	11	11.0%	23	13.5%	83	36.1%
	Rather Yes	26	26.0%	49	28.8%	104	45.2%
	Rather No	43	43.0%	50	29.4%	29	12.6%
	No	19	19.0%	44	25.9%	13	5.7%
Multidisciplinary BPSD management conference	Yes	20	20.0%	49	28.8%	15	6.5%
	Rather Yes	25	25.0%	48	28.2%	44	19.1%
	Rather No	30	30.0%	45	26.5%	126	54.8%
	No	18	18.0%	26	15.3%	39	17.0%

4. Discussion

The study marks the initial exploration of the current situation of palliative care for older adults with advanced dementia. Across GHs, GHSFs, and HNCSs, staff education about dementia and palliative care is notably lacking. Although many reported implementing a standardized ACP format, very few acknowledged providing spiritual care to older clients with dementia. This study demonstrates variations in current palliative care practices among these settings in Japan. Despite increased attention during the COVID-19 pandemic, community-based ACP support services are not widely provided among GHs, GHSFs, and HNCSs. Given the frequent transitions of older individuals with advanced dementia between healthcare settings, sharing ACP information among clinicians across healthcare settings is essential for understanding individual preferences for end-of-life care. HNCSs cover a broad range of domains of palliative care for patients with advanced dementia; they focus on caring for family caregivers, the spiritual domain of patients, and pain management. However, few GHs and GHSFs support family participation and spiritual care.

The results highlight a surprisingly low prevalence of dementia care and palliative care education across healthcare settings (i.e., acute care hospitals, nursing homes, and home care support services); this may stem from a lack of clear definitions for staff education. The interpretation of the results should be generalized with attention to the informal or "hidden" curriculum. This involves the influences of peers, role models, and norms and practices related to the values, attitudes, beliefs, and behaviors constituting the culture of palliative care for people with dementia.

While many of them reported using a standardized ACP form at their workplace, very few participants provided spiritual care to older clients with dementia. There are two possible explanations for this observation. Firstly, ACP could have been examined via a narrower scope. Historically, the measure of ACP success has been the documentation of living wills or advance directive forms. These documents use checkboxes to outline individual preferences for life-sustaining treatments such as cardiopulmonary resuscitation and mechanical ventilation [36]. A living will is a legal document that details a patient's decisions on issues such as pain management or medical treatments that a patient would or would not like to receive as death approaches. Advance directive forms allow individuals to designate a surrogate decision-maker in cases of decisional incapacity. However, the definition of ACP is now broader than a singular moment or document that supports patients in understanding and sharing their values, life goals, and preferences regarding future medical care [36]. Secondly, the lack of a clear definition of spiritual care may have hindered participants from recognizing their spiritual care practices for older people with dementia. Although spirituality attends to an individual's religious needs as they cope with illness, loss, grief, or pain [37], it is often thought of as religion alone [38].

The results imply that HNCSs could cover a broad range of domains of palliative care for patients with advanced dementia, focusing on care for family caregivers, the patients' spiritual domain, and pain management. Generally, nurses are central to primary health care and form a part of their local community, sharing their culture, strengths, and vulnerabilities. Because of this, they can curate and deliver effective interventions to meet the holistic needs of patients, families, and communities [39]. In one study [40], nurses in home care were more likely to provide patients with social and spiritual care at the end of their lives than those in hospitals. The higher tendency of HNCSs to provide care for family caregivers and spiritual care for patients could be because people often prefer to stay at home and spend the last months of their lives at their own pace. Patients at home feel more at ease and can discuss their preferences, needs, and values, which influence the provision of social and spiritual care.

The results further revealed that few GHs and GHSFs supported family participation in palliative or spiritual care. There is a wealth of literature investigating the role of family involvement in LTC facilities following the placement of a relative with dementia [41]. Barriers to family participation in the facilities included lower visit frequency, poor communication with staff, and social distancing measures due to the COVID-19 pandemic [42,43]. The lower rate of spiritual care provision among GHs and GHSFs could be because healthcare professionals in such facilities have easier access to other members who provide spiritual support for patients.

Poorly treated pain is not only distressing but also impairs social interactions, quality of life, appetite, and sleep and is implicated in BPSD [44]; therefore, both pain and BPSD should be assessed in the palliative care of patients with advanced dementia. Interestingly, the HNCSs in this study often provided multidisciplinary pain and symptom management discussions in palliative care, whereas they organized multidisciplinary BPSD management conferences less frequently. The discrepancy in symptom management discussion and BPSD conference attendance could be because care managers in home care support offices are obliged to host multidisciplinary case conferences regularly under the Japanese LTC insurance system. Hence, the nurses in HNCSs attended rather than hosted multidisciplinary BPSD conferences.

The strength of our study lies in the rigorous data collection and analysis, which were maintained as we collected quantitative data from a nationwide sample. Furthermore, the research team members thoroughly discussed the selection of questionnaire items until a full consensus was reached. In addition, our research team members represented diverse professional backgrounds—physicians, nurses, care managers, social workers, lawyers, and volunteers.

This study is not without limitations. One of these limitations is that palliative care provision for patients with dementia across all types of LTC settings has been affected by the COVID-19 pandemic. Furthermore, the low response rate of the survey may have introduced some bias into the study results due to differences between responders and non-responders. Additionally, the research team, including the Japanese authorities of palliative care for older adults, may have introduced a social desirability bias by over-reporting good behavior or under-reporting bad behavior. Bias is more likely to occur when the topic of the survey is ethically sensitive, such as death. Moreover, owing to the lack of data on the quality and quantity of care provision, the study results should be generalized with caution. In addition, because the respondents were only head nurses, the answers might not necessarily reflect the actual situation because of a lack of multidisciplinary or on-site perspectives. Other professionals may have expressed opinions different from those of the respondent nurses. The study participants also did not include other relevant facilities, such as nursing homes and group homes for older individuals with dementia, due to time and financial restrictions. Finally, recall bias could have been a problem as the study relied on self-reporting. It is possible that some respondents worked at facilities with regressive policies toward palliative care provision, which could have made them incorrectly recall their palliative care practices.

5. Conclusions

This study demonstrates that current palliative care practices for older adults with dementia vary among GHs, GHSFs, and HNCSs in Japan. HNCSs cover a broad range of palliative care domains for patients with advanced dementia, including spiritual care and care for family caregivers. However, only a few GHs and GHSFs provided support for family participation in palliative or spiritual care. This finding underscores the need for targeted improvements in palliative care for patients with dementia across LTC settings in Japan. Further studies should include other relevant facilities for older individuals with dementia to generate more generalizable results.

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