

Original article

A qualitative study on barriers to achieving high-quality, community-based integrated dementia care

Yoshihisa Hirakawa¹, Chifa Chiang¹ and Atsuko Aoyama¹

¹Department of Public Health and Health Systems, Nagoya University Graduate School of Medicine, Japan

Abstract

Introduction: High-quality, community-based dementia care requires a comprehensive, holistic approach. This study aimed to identify the barriers to achieving efficient cooperation and coordination among medical professionals, care managers, and medical social workers, and to improve the management model of community-based, integrated dementia care.

Methods: We collected qualitative data through three focus group discussions at JA Konan Kosei Hospital. Thirteen participants (four directors of nursing service departments, three chief nurses, four medical social workers, and two care managers) were recruited for the discussions. The data were analyzed using an inductive, multi-step approach referred to as the qualitative content analysis.

Results: Nine themes arose as follows: little attention given to patient wishes, lack of time and space to provide high-quality care, disturbing hospital environment, poor compensation for staff members, refusing to visit outpatient clinics, declined admission, daily life support by family members and caregivers, dementia care team, and community bonding.

Conclusion: The participants wanted to launch a dementia care team in their hospital to improve the care environment and the quality of dementia-specific care. The study also suggested that advance care planning could be systematically implemented in clinical practice as a way to honor the decisions made by dementia patients.

Key words: community-based integrated care, dementia, strategy, hospital nurse

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Introduction

More than 3.45 million people in Japan live with dementia, a number that has been on the rise in recent years^{1, 2}. Elderly people with dementia experience a deterioration of their clinical condition associated with complex physical, mental, and social problems^{3–5}. The complexity of the disease and the wide variety of living arrangements among patients make it difficult for people with dementia and their families to cope with the disease. It is urgent to find a way to ameliorate the mounting financial and social burden.

High-quality, community-based dementia care requires a comprehensive, holistic approach^{5, 6}. This type of care must be undertaken through a community-based integrated care system^{3, 4}. The system is a new concept for the provision of care services for the elderly. Japan's community-based integrated care system is defined as “a community-based system designed to secure suitable living arrangements and appropriate social care such as daily life support services as well as long-term medical care, in order to ensure the health, safety, and peace of mind of the elderly in their everyday life”. The system is expected to increase cost efficiency and to improve the quality of life of the elderly with dementia.

However, in spite of the many efforts made to rationalize and improve the performance and quality of the community-based integrated care system, only a limited degree of success has been achieved thus far^{4, 6–8}. The various health care and social care components responsible for the provision of dementia care in Japan have been described as fragmented and poorly coordinated by a number of recent studies^{2–4}.

This study aimed to identify the barriers to achieving efficient cooperation and coordination among medical professionals, including nurses, physicians, care managers, and medical social workers, regarding all aspects of care for the individual, as well as to improve the management model of community-based, integrated dementia care.

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Correspondence: Yoshihisa Hirakawa, Department of Public Health and Health Systems, Nagoya University Graduate School of Medicine, 65 Tsuruma-cho, Showa-ku, Nagoya, Aichi 466-8560, Japan
E-mail: y.hirakawa@med.nagoya-u.ac.jp

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Methods

We collected qualitative data through three focus group discussions at JA Konan Kosei Hospital, an educational district hospital providing a wide range of medical services. The discussions were held in March 2016. Thirteen participants were recruited for the discussions, including four directors of nursing service departments, three chief nurses, and four medical social workers from the hospital. We also recruited two care managers from facilities affiliated with JA Konan Kosei Hospital. Care managers are a group of professionals responsible for drawing up care plans and coordinating long-term care services for individual clients under Japan's long-term care insurance system^{9, 10}. We selected participants from the three professions, *i.e.*, nurses, social workers, and care managers, because of their important roles in managing community-based, integrated dementia care in hospitals. Focus group discussions were conducted until all participants agreed that they had no more ideas. The discussions lasted about 60 minutes.

During the discussions, the participants were asked to actively speak up and write down all of their ideas and thoughts on community-based, integrated dementia care. Then, based upon these written notes, each participant created a complete list of ideas and thoughts generated during the exchange. Finally, the participants' ideas and thoughts were transferred to individual labels.

Analysis

The data were analyzed using an inductive, multi-step approach referred to as the qualitative content analysis¹¹. The process began with several readings of the labels to proofread them and arrange them into meaning units. This allowed us to familiarize ourselves with the overall content of the data. Subsequently, meaning units were arranged into common meaning groups in order to identify larger themes emerging from the data. The final steps involved reviewing themes, cross-checking for overlap, and defining and naming themes. In order to avoid relying on a single researcher's interpretation of the data, a consensus approach was used. At each stage of the process, the findings were discussed with the other authors and the interview participants to make sure they were interpreted accurately.

This study was approved by the Bioethics Review Committee of the Nagoya University School of Medicine before the investigation (approval number 2015-0444).

Results

After grouping, nine themes arose as follows: little at-

attention given to patient wishes, lack of time and space to provide quality care, disturbing hospital environment, poor compensation for staff members, refusing to visit outpatient clinics, declined admission, daily life support by family and caregivers, dementia care team, and community bonding (Table 1).

Little attention given to patient wishes

People with dementia often have difficulty expressing their wishes. Physicians or nurses tend to consult a surrogate, rather than the patient with dementia, due to communication difficulties.

Lack of time and space to provide quality care

Nurses and family caregivers are eager to treat people with dementia kindly. However, they often lack the time and space to provide high-quality care to dementia patients, which makes them feel stressed and dissatisfied.

Disturbing hospital environment

Dementia patients may find hospitals uncomfortable, as they often lack spaces for them to relax. When dementia patients are relocated from their home to a hospital, they often become anxious and confused when trying to find a toilet or their room.

Poor compensation for staff members

Additional funds would enable hospitals to hire and train interdisciplinary staff and improve their team-based approach.

Refusing to visit outpatient clinics

People with dementia often refuse to go to an outpatient clinic. Since they often have no subjective symptoms, they are unlikely to accept a recommendation to visit an outpatient clinic.

Declined admission

A declining health condition and the sudden change in environment upon hospital admission can trigger behavioral and psychological symptoms of dementia (BPSD) in people with dementia. People with BPSD are often refused admission to hospitals or nursing homes for safety and management reasons.

Daily life support by family and caregivers

Dementia care requires high-quality, well-integrated medical and social services to support the daily lives of people with dementia. Sharing patient information with the people who care for the patient on a daily basis is necessary to build a dementia-friendly community.

Table 1 Barriers to achieving high-quality, community-based integrated dementia care

Thema	Category	Meaning unit	
Little attention given to patient wishes		In some cases, care providers favor family preferences over elderly patient wishes	
Lack of time and space to provide quality care	Family caregivers are too busy to properly take care of their loved ones with dementia	Family caregivers are so busy with work and daily life constraints that they are at times irritated with their elderly relatives with dementia	
		Family caregivers unavoidably get angry with their elderly relatives with dementia even though they recognize that dementia is the cause of their behavioral disorder	
		Caregivers often feel unappreciated and stressed because elderly people with dementia are unable to show gratitude	
	Frequently shorthanded, hospital nurses often feel sorry for not being able to properly care for dementia patients	We are not really sure that physically restraining elderly patients with dementia is a sound treatment option	
		There are few opportunities for hospital nurses to discuss dementia-specific care at daily meetings	
		Hospital nurses are too busy caring for severe patients to properly look after elderly patients with dementia	
		If I had enough time to listen to patients with dementia I could get a better grasp of their situation and that of their family caregivers	
		Elderly patients with dementia often display behavioral and psychological symptoms of dementia (BPSD) at our busiest times, such as meal time, early morning or midnight.	
Disturbing hospital environment	We need to make the hospital environment suitable and comfortable for patients with dementia	We think that the hospital environment triggers anxiety and fear in people with dementia	
		We need to create an area where people with dementia can enjoy communicating with others in our hospital	
Poor compensation	Dementia-related medical service fees are too low to ensure quality dementia care	The current home-visit medication counseling system for dementia is not adequate to ensure that patients properly adhere to their prescriptions	
		We hope dementia-related medical service fees increase	
Refusal to visit outpatient clinic	People with dementia often refuse to visit outpatient clinics and it is difficult to convince them to go	Because people with possible dementia often refuse to visit outpatient clinics, it is difficult to take them there.	
		We hope that dementia specialists carry out home visits because it is difficult for caregivers to take people with dementia to outpatient clinics	
Hospital admission refusal	Behavioural and psychological symptoms of dementia (BPSD) are a possible cause of hospital admission refusal	The hospital environment can at times worsen the behavioral and psychological symptoms of dementia	
		People with dementia are often refused admission for safety reasons	
Daily life support by family and carers	Improved collaboration between hospitals, integrated comprehensive care centers, and care service providers is needed	A person with possible dementia can be introduced to a hospital integrated comprehensive care center by a nurse and start receiving care services	
		Some hospitals or care service providers monopolize elderly clients with dementia and do not share information in the community	
	Ensuring the safety of people with dementia in the community is a pressing concern	In order to locate older people with dementia who have gone missing, we want to use a GPS (Global Positioning System)	
		Following the recent rise in dementia-related train and car accidents, we worry about the safety of people with dementia and ordinary citizens	
	Specialist physicians should show more interest in the daily lives of people with dementia		At general hospitals, physicians focus on their own specialty and do not offer comprehensive dementia care
			Physicians show little interest in the daily lives of people with dementia
			We want physicians to share information on elderly patients with dementia
			Dementia education should be mandatory in schools and companies
Dementia care team	We need dementia care consultants at our hospital and wards	Chief hospital administrators are not familiar with the educational needs and methodology of dementia care	
		We need a dementia specialist in each hospital ward	
	There is a severe shortage of dementia specialist physicians	In addition to visits from a psychiatrist three times a week at our hospital, we need a doctor to consult on daily basis	
Community bond	We cannot collect information on people with dementia living at home unless family caregivers provide it	Our hospital requires a full-time geriatrician or a psychiatrist to take care of dementia patients	
		People with cognitive impairment who live on their own or with a spouse tend to be overlooked	
		It is difficult for health care providers to closely monitor the daily living situation of people with dementia who live on their own	
		Families are reluctant to let others know that their loved one suffers from dementia	

Dementia care team

The concept of a “dementia care team” is not widely spread in Japan. Dementia care requires a comprehensive assessment from a team of specialists, including neurologists, geriatricians, nurses, and social workers. The participants recognized the need for a dementia care team involved in decisions regarding medications, family and staff education, and consulting.

Community bonding

Elderly people living alone are vulnerable to social isolation. Physicians, nurses, and care managers are often unaware of changes in their patients’ health condition due to lack of communication. A community network, including a neighborhood watch, is an effective means of monitoring the health condition of elderly patients at risk of isolation.

Discussion

This qualitative study explored the ideas of hospital nurses, medical social workers, and care managers related to the barriers to achieving high-quality, community-based integrated dementia care. The study revealed that the participants wanted to launch a dementia care team in their hospital to improve the care environment and the quality of dementia specific care, indicating their awareness of the shortcomings of the current situation. The study also highlighted the fact that advance care planning (ACP)¹²⁾ should be systematically implemented in clinical practice as a way to honor the decisions made by dementia patients, which are often overlooked by physicians and nurses. Moreover, we found that proactive involvement of the community was a driving force behind high-quality, community-based integrated dementia care. Overall, our results indicated that inter-hospital and hospital-community collaboration were key factors in overcoming the barriers to a high quality of life of the elderly with dementia.

Our results revealed that a collaborative transdisciplinary team approach for dementia care was required in the hospital. Although collaborative dementia care models have been widely recognized in primary care settings³⁻⁷⁾, the services provided by hospital physicians, nurses, and social workers tend to be independent¹³⁾. Indeed, our results indicated a lack of collaboration between physicians of different departments. Our study also revealed that physicians were often indifferent to the social aspects of the lives of people with dementia. Previous studies indicated that physicians lack the necessary time to spend on dementia care^{5, 7, 14)}. Calling upon other team members for assistance could offset physician time and facilitate meeting the needs of patients and caregivers more effectively⁷⁾.

The participants expressed the need to have access to dementia specialist physicians, such as neurologists and geriatricians, for consultation about dementia care. General physicians are not particularly knowledgeable about dementia care and they have limited time to devote to it; as a result, they find it challenging to offer appropriate diagnoses and treatments to dementia patients⁵⁾. Galvin *et al.* suggested that the dementia care team include a neuropsychologist to support the general physician’s decisions regarding dementia-related diagnosis, treatment, and counseling⁷⁾. Reuben *et al.* report that at the University of California at Los Angeles (UCLA) program¹⁵⁾, all patients benefit from a dementia care management program led by a nurse practitioner and supervised by a dementia specialist physician. The program includes the implementation of a care plan, monitoring, counseling, and caregiver education.

Our results suggested that hospital nurses and family caregivers experienced difficulty in the management of BPSD. They generally agreed that there was not enough time and space to provide appropriate care, and they often felt disappointed about not being able to meet their patients’ needs. Teaching them how to deal with this type of work-related stress could help reduce the burden on caregivers¹⁶⁾. The participants indicated that the dementia care team was also expected to reduce BPSD and the caregiver burden of families and hospital nurses.

High-quality dementia care relies upon efficiency and promptness of response. Several studies emphasized the benefits of a team-based approach focused on comprehensive assessment tools to measure and monitor patient and caregiver needs and response to interventions^{5, 7, 15)}. Awata *et al.* developed a 21-item Dementia Assessment Sheet for Community-based Integrated Care System (DASC-21)⁴⁾. Comprehensive geriatric assessment is defined as a multidisciplinary diagnostic and treatment process that identifies medical, psychosocial, and functional limitations of a frail older person in order to develop a coordinated plan to maximize overall health with aging^{17, 18)}. Comprehensive Geriatric Assessment is based on a systematic evaluation of frail older persons by a team of health professionals.

One study participant mentioned that, in some cases, health care providers prioritize the wishes of families rather than those of the dementia patients. This underscores the importance of ACP among people with dementia. ACP is a process that enables individuals to convey their preferences and plans about their future health care and end-of-life care to family caregivers and health care professionals¹⁹⁾. ACP is also of particular importance for elderly people with dementia because many of them will decline progressively to a state in which they can no longer communicate their end-of-life care preferences²⁰⁾. Previous studies have shown that

discussions about ACP and surrogate decision-making are quality indicators of dementia care⁵). Galvin *et al.* suggested that decision-making should be shared among physicians, nurses, social workers, and families⁷). Under the Japanese long-term care insurance system, care managers are responsible for developing a daily care plan that includes ACP²¹). The UCLA program also includes a decision-making support process led by nurse practitioners and dementia care managers^{5, 15}).

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References

1. Ministry of Health, Labour, and Welfare. Number of elderly persons with dementia. Available at: <http://www.mhlw.go.jp/stf/houdou/2r9852000002iau1.html>. Accessed January 5, 2017 (in Japanese).
2. Nakanishi M, Nakashima T. Features of the Japanese national dementia strategy in comparison with international dementia policies: How should a national dementia policy interact with the public health- and social-care systems? *Alzheimers Dement* 2014; 10: 468–476.e3. [[Medline](#)] [[CrossRef](#)]
3. Maki Y, Yamaguchi H. Early detection of dementia in the community under a community-based integrated care system. *Geriatr Gerontol Int* 2014; 14(Suppl 2): 2–10. [[Medline](#)] [[CrossRef](#)]
4. Awata S, Sugiyama M, Ito K, *et al.* Development of the dementia assessment sheet for community-based integrated care system. *Geriatr Gerontol Int* 2016; 16(Suppl 1): 123–131. [[Medline](#)] [[CrossRef](#)]
5. Jennings LA, Tan Z, Wenger NS, *et al.* Quality of Care Provided by a Comprehensive Dementia Care Comanagement Program. *J Am Geriatr Soc* 2016; 64: 1724–1730. [[Medline](#)] [[CrossRef](#)]
6. Backhouse A, Dickens C, Richards D, *et al.* Key components in models of community-based interventions coordinating care in dementia: a mixed studies systematic review protocol. *Syst Rev* 2015; 4: 156. [[Medline](#)] [[CrossRef](#)]
7. Galvin JE, Valois L, Zweig Y. Collaborative transdisciplinary team approach for dementia care. *Neurodegener Dis Manag* 2014; 4: 455–469. [[Medline](#)] [[CrossRef](#)]
8. Plochg T, Klazinga NS. Community-based integrated care: myth or must? *Int J Qual Health Care* 2002; 14: 91–101. [[Medline](#)] [[CrossRef](#)]
9. Igarashi A, Ishibashi T, Shinozaki T, *et al.* Combinations of long-term care insurance services and associated factors in Japan: a classification tree model. *BMC Health Serv Res* 2014; 14: 382. [[Medline](#)] [[CrossRef](#)]
10. Yamada M, Hagihara A, Nobutomo K. Family caregivers and care manager support under long-term care insurance in rural Japan. *Psychol Health Med* 2009; 14: 73–85. [[Medline](#)] [[CrossRef](#)]
11. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004; 24: 105–112. [[Medline](#)] [[CrossRef](#)]
12. Detering KM, Hancock AD, Reade MC, *et al.* The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; 340: c1345. [[Medline](#)] [[CrossRef](#)]
13. Hattori H. Role of geriatric hospitals for dementia care in the community. *Psychogeriatrics* 2012; 12: 124–126. [[Medline](#)] [[CrossRef](#)]
14. Grand JH, Caspar S, Macdonald SW. Clinical features and multidisciplinary approaches to dementia care. *J Multidiscip Healthc* 2011; 4: 125–147. [[Medline](#)]
15. Reuben DB, Evertson LC, Wenger NS, *et al.* The University of California at Los Angeles Alzheimers and Dementia Care program for comprehensive, coordinated, patient-centered care: preliminary data. *J Am Geriatr Soc* 2013; 61: 2214–2218. [[Medline](#)] [[CrossRef](#)]
16. Spencer K, Foster P, Whittamore KH, *et al.* Delivering dementia care differently evaluating the differences and similarities between a specialist medical and mental health unit and standard acute care wards: a qualitative study of family carers perceptions of quality of care. *BMJ Open* 2013; 3: e004198. [[Medline](#)] [[CrossRef](#)]
17. Stuck AE, Siu AL, Wieland GD, *et al.* Comprehensive geriatric assessment: a meta-analysis of controlled trials. *Lancet* 1993; 342: 1032–1036. [[Medline](#)] [[CrossRef](#)]
18. Devons CA. Comprehensive geriatric assessment: making the most of the aging years. *Curr Opin Clin Nutr Metab Care* 2002; 5: 19–24. [[Medline](#)] [[CrossRef](#)]
19. Takeshita Y, Ikeda M, Sone S, *et al.* The effect of educational intervention regarding advance care planning for advance directives. *Health* 2015; 7: 934–945. [[CrossRef](#)]
20. Dening KH, Jones L, Sampson EL. Advance care planning for people with dementia: a review. *Int Psychogeriatr* 2011; 23: 1535–1551. [[Medline](#)] [[CrossRef](#)]
21. Watanabe M, Yamamoto-Mitani N, Nishigaki M, *et al.* Care managers confidence in managing home-based end-of-life care: a cross-sectional study. *BMC Geriatr* 2013; 13: 67. [[Medline](#)] [[CrossRef](#)]