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

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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

Introduction

More than 3.45 million people in Japan live with dementia, a number that has been on the rise in recent years¹ - ². Elderly people with dementia experience a deterioration of their clinical condition associated with complex physical, mental, and social problems³ - 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 approach⁵, ⁶. This type of care must be undertaken through a community-based integrated care system³, 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 far⁴, 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 studies² - 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.
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 system5, 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 analysis13. 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 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

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

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 patients. 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 counseling. Reuben et al. report that at the University of California at Los Angeles (UCLA) program, 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 caregivers. 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. Awata et al. developed a 21-item Dementia Assessment Sheet for Community-based Integrated Care System (DASC-21). Comprehensive geriatric assessment is defined as a multi-disciplinary 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. 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 professionals. 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 preferences. Previous studies have shown that...
discussions about ACP and surrogate decision-making are quality indicators of dementia care\(^5\). Galvin et al. suggested that decision-making should be shared among physicians, nurses, social workers, and families\(^7\). Under the Japanese long-term care insurance system, care managers are responsible for developing a daily care plan that includes ACP\(^21\). The UCLA program also includes a decision-making support process led by nurse practitioners and dementia care managers\(^5, 15\).

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