

## Abstract of Master's Dissertation

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Course	Health Innovation Course	Name	Marin Ohira
Thesis Title	<p>Exploring a Community-based Integrated Care System for the moderate-to-severely-disabled elderly to realize their lives as they want</p> <p style="text-align: center;">- Focusing on their <i>Ikigai</i> and role in family and community -</p>		
<p><b>Background and Purpose:</b> With the increasing number of the elderly in Japan, the government promotes a community-based integrated care system (CICS) for the elderly with long-term care (LTC) so they may live at home as long as possible with the community services. For the moderate-to-severely-disabled elderly (MSDEs), however, it is not easy to live at home.</p> <p><b>Objectives:</b> This study is to explore the role and ikigai of community dwelling MSDEs in the CICS. The study hypothesized that having the role and ikigai after needing LTC makes MSDEs want to continue to live at home.</p> <p><b>Methods:</b> A qualitative study was undertaken by semi-structured interviews and observation in Nagasaki city, Japan. Seven MSDEs who live at home, 3 males and 4 females, aged 70 to 95, 4 at care level 3 and 3 at care level 4 were studied. Their Japanese independence degree of daily living for the disabled elderly ranged A2 to B2. Their degree of daily living for the demented elderly were I to IIIa except one non-case. Their carers, six family members living together with MSDEs, and one care manager for single dweller, and a total of 18 social resource persons, local government staff including community-general support centre staffs, long-term care insurance (LTCI) staffs, a person from residents' association, a member of an elderly club, welfare commissioners, and a social welfare council staff, were interviewed. Interviews with MSDEs were conducted 2 to 4 times per person, from 40 to 120 minutes long for each session. Case history was taken for each MSDE. Barriers to realizing their lives as they want were identified. The elderly's role and <i>ikigai</i> were extracted from the interviewed records. Interviews were conducted with carers (30 to 80 minutes per session), care managers of all participants to see the difference of perceptions on their service situation and ADL status between MSDEs and their families. MSDEs' roles, ikigai and hope for the future (how and for what they want to live), along with their past roles and ikigai were studied. Then, the relationship of the role and ikigai of MSDEs with CICS were sought out.</p> <p><b>Findings and conclusion</b></p> <p><b>Changing role of MSDEs:</b> Most MSDEs had more interactions with communities before the development of illness and LTC needs. Their lives changed due to their illness and LTC needs. They and their family took certain time to accept the new situation and started to work positively. All of MSDEs use LTCI services at least 2 days per week. All of them (except the single dweller) want to stay at home with their families, and all want to live at home until the end if possible. Carers know what MSDEs' desire and try to look after them as much as</p>			

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<p>possible. At the same time, carers often feel anxiety about whether LTC at home can be continued. Some of them have opinions that MSDEs should enter LTCI facilities if the carer is sick or if MSDEs’ deteriorates. Carers often feel the number of carers is insufficient, regardless of the number of relatives, friends, etc. Even though MSDEs and their carers feel that using the current public services alone are not sufficient to support MSDEs living at home, using these services helped to maintain and improve living conditions of MSDEs and to provide respite care for their families. While some use the services actively and willingly, others have negative feelings and are bored of the service, saying ‘I do not want to go.’ However, even those unwilling to use the service tend to passively accept its use giving their families a break.</p> <p><b>MSDEs’ Role and <i>Ikigai</i>:</b> The roles and <i>ikigai</i> they had when MSDEs were healthy may need to be left behind. However, they may cultivate new roles and <i>ikigai</i> based on their new state. MSDEs feel that they cannot do anything compared with their previous state. They also recognize, however, their own role as care-receivers to prevent worsening of their condition and not to increase family's care burden. Moreover, they feel their role in connection with families and communities by showing appreciation and by passing on wisdom to the younger generation. Maintaining their ADLs itself became <i>ikigai</i>. Even after MSDEs need LTC and lose former <i>ikigai</i>, they try to maintain a willingness to live, to gain a small victory feeling by improving their lives.</p> <p>Their family and social resources, who are in contact with the disabled elderly, can recognise the elderly's <i>ikigai</i> in their expressions and attitudes, even if the disabled cannot express it in words. LTCI staffs other support people are aware that it is necessary to draw out the feelings of MSDEs—what they want and how they want to live.</p> <p>MSDEs feel <i>ikigai</i> in interaction with familiar persons, activities of pastime mostly in day-care service, activities of daily life such as taking bath and ritual activities. They are motivated to continue living by feeling <i>ikigai</i> in their lives. This seemed a reason why the seven MSDEs in this study are able to stay at home. In general, the family members and social resources tend to think MSDEs lose their role when they become care-receivers. However, the family members and social resources also recognize MSDEs’ role through their display of gratitude.</p> <p><b>Promotion of CICS:</b> To promote CICS, the city has acted section-widely in collaboration with relevant organization according to the task. CICS components, medical care, LTC, preventive care, livelihood support and housing support services, are mutually related and cooperate to support the life at home.</p> <p>When a person needs LTC, interaction with community other than LTCI services is likely to be broken. CICS city investigators asked desired type of LTC to families, but not to the disabled elderly. A social resource point out the necessity to raise awareness in the elderly about their future involvement in their own care. For further improvement of CICS, the following issues</p>			

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<p>were found in this study. Insufficient cooperation between medical care and LTC such as the time of hospitalization (entering and leaving), lack of quality and quantity of human resources related to LTCI services, the physical environment such as slopes, shop steps, and kerbs, and the difficulty for local residents to accept MSDEs because of lack of experiences with MSDEs.</p> <p><b>Conclusion:</b> While the MSDEs felt that they cannot do anything because of their disability, they wished to live at home, have new meaningful roles, and ikigai. With their disability, they tend to have difficulty in maintaining relationships with the community. This makes home care difficult. Under CICS, it is necessary to tailor care to each individual and to support MSDEs and their families at home directly at the community.</p> <p>※ Since the main contents were not revised, it may differ somewhat from this abstract.</p>			