

A research to build a post-diagnostic support system in the community
for the people with early-onset dementia

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Abstract

The purpose of this study is to make policy recommendations toward building a comprehensive cross-system social support for people with early-onset dementia and their families. Eighteen institutions, organizations, and professionals (early-onset dementia support coordinators, long-term care insurance service offices, disability welfare service offices, independent businesses corporation, and family associations) that are pioneering support for people with early-onset dementia participated this study from February to November 2022. We held online meetings which consisted of 15 case presentations. After verbatim records of the case presentations and discussions was made, thematic analysis was conducted, and 10 categories were generated. From this thematic analyses, we suggest the policy recommendations which includes: 1) a social care to deliver tailor-made support, not focused to the people with early-onset dementia only, but for the variety of people with various challenges across age, disability, etc.; 2) seamless support for the people with early-onset dementia through collaboration between medical social workers and psychologists at specialized medical centers for dementia disease, etc.; 3) strategic configuration of community resources such as support coordinators for early-onset dementia, small-scale multifunctional in-home care, and community activity support centers, to enable them to work as a system.

1. Aim

The purpose of this study is to make policy recommendations that contribute to a system of cross-system support for individuals with early-onset dementia and their families.

2. Methods

1) Participants

In 2019, as a project of the Tokyo Metropolitan Government, a questionnaire survey on support for people with early-onset dementia was conducted on 3,668 nursing care insurance service offices, welfare service offices for persons with disabilities, NPO organizations, etc. to find best practice in Tokyo. We found several organizations that were delivering best practice, and invited them to the case study search meetings. Representatives from a total of 18 institutions, businesses, and organizations that agreed with the purpose of the study, as well as researchers from the Tokyo Metropolitan Institute of Gerontology, participated in the meetings.

2) Procedure

The case study meetings were conducted online, and case reports and discussions were transcribed verbatim.

3) Analysis

The MAXQDA 2022 was used for the verbatim transcripts, and a thematic analysis of the support and efforts made for individuals and families with early-onset dementia was conducted.

4) Ethical consideration

Case reports were presented anonymously, which do not contain any personal information. In addition, none of the participants were forced to present cases and actually some participants did not report any cases

3. Results

1) Case Study Meetings

A total of 12 case study meetings were held between February and November 2022, with 15 cases reported. The total number of participants was 104, with an average of 8 participants.

2) Themes

The following categories were generated.

- ▼ Communal support for diverse ages and disabilities to live well together.
- ▼ Family caregiver support who might have negative emotions
- ▼ Supporting each other through equal relationships (peer support)
- ▼ Creating a comfortable place and expressing the desire for self-fulfillments
- ▼ Support where personal choice is protected, no choices forced.

- ▼ Creation of a place of freedom, where people can come even if they have no purpose and talk with professionals even if they have nothing to discuss.
- ▼ Employment support along with their symptom progression
- ▼ Harm of stereotype understanding of early-onset dementia
- ▼ Difficulties in detecting people with early-onset dementia
- ▼ Limitation of present legal system

4. Future policy framework

We suggest following social implementation efforts;

- 1) a social care to deliver tailor-made support, not focused to the people with early-onset dementia only, but for the variety of people with various challenges across age, disability, etc.;
- 2) seamless support for the people with early-onset dementia through collaboration between medical social workers and psychologists at specialized medical centers for dementia disease, etc.;
- 3) strategic configuration of community resources such as support coordinators for early-onset dementia, small-scale multifunctional in-home care, and community activity support centers, to enable them to work as a system.