

主論文の要旨

**Everyday wishes of older people living with dementia
in care planning: a qualitative study**

〔 認知症高齢者の日常生活の希望に関する質的研究 〕

名古屋大学大学院医学系研究科 総合医学専攻
社会生命科学講座 国際保健医療学・公衆衛生学分野

(指導：八谷 寛 教授)

Md. Razib Mamun

【Background】

Globally, the number of older people living with dementia (PLwD) is increasing. The dementia care policy in Japan emphasizes the views of people living with dementia in care planning. However, the everyday wishes of PLwD are ignored because little is known about the individual everyday wishes of older PLwD. An exploration of the everyday wishes of older PLwD can help clarify their priorities and assist in improving dementia care. Therefore, this study aimed to explore the everyday wishes of older people living with dementia in Japan in order to inform caregivers, families, and service providers how PLwD can be supported more by delivering care in line with their wishes.

【Methods】

In this study, we applied a qualitative methodological approach to explore the everyday wishes of PLwD. A dementia outpatient clinic in Aichi prefecture in central Japan was conveniently selected for the recruitment of participants. In-depth interviews with PLwD were conducted in the same outpatient clinic from January to October 2019. Older people with mild to moderate dementia were considered for inclusion. Convenience sampling was used to recruit participants. The sample size was determined using the data saturation model. Up to data saturation, we interviewed 36 participants. Data were collected using a pre-specified topic guide.

All recorded interviews were transcribed verbatim in Japanese and then translated into English. In this study, an inductive content analysis was performed. The analysis started with open coding. Two researchers coded each transcript independently. The codes were then categorized into sub-categories based on their similarities and differences. Similar sub-categories were grouped and labeled as categories. Finally, the categories were summarized and developed themes.

【Findings】

Most of the participants were aged between 80 and 89 years (80.5%) and female (83.3%). The HDS-R scores of the participants were ranged from 9 to 14 (36.1%) and 15–20 (63.9%). From the qualitative data analysis of interviews, 168 primary codes emerged. The study findings were organized under five themes: desire of being connected, freedom to decide, involvement in activities, status quo, and self-reliance.

Desire of being connected

The participants described the theme ‘desire of being connected’ from two perspectives: (1) the importance of living with family (2) attachment with family and friends. The desire of being connected in everyday life was stated as the most important wish by all participants. Participants informed that they had people to look after them and talked about the help that

family members did. They recognized the importance of this assistance in getting through everyday life. Presence, mutual conversation, do something together were considered as the connection. Besides family, connection with friends was considered a vital everyday wish among participants.

Freedom to decide

The majority of participants mentioned that they were not allowed to make decisions about their daily activities, such as where and with whom to visit and their participation in social activities. Participants indicated a wish for more freedom in their daily lives. Having freedom meant having control over their daily schedule and activities in daily life. Many participants, for example, requested more control over having a say in when and how they participate in preferred activities, such as attending a baseball game, going shopping, or going on a day trip, even if they had to depend on others for transportation or other support.

Involvement in activities

Spending a day without doing anything could be emotionally painful for many participants. They talked about activities they wanted to carry forward for having an enjoyable time. The preferences regarding enjoyable activities differ among participants. Most participants expressed a desire to have a daily routine and wish to involve with something pleasant regularly, like going to a daycare center, gardening, taking a walk, playing a game, visiting different places, etc.

Status quo

A status quo bias is an emotional effect that makes the participants worried that something might be lost due to change. Participants focused on having everyday life run as usual. Their habits, routines, and familiar environment were crucial to them, and they wanted to keep them unchanged.

Self-reliance

The idea of self-reliance was strong among the participants. Many of them stated that they would prefer to die instead of becoming troublesome. The participants also wanted to live on their own without being a burden to others. Notably, if they become a burden on their family and require assistance in every aspect of their daily lives, that could create conflict between them and their family when they differ in their preferences for activity which will eventually force them to follow the instruction of family members.

【Discussion】

This study explored the everyday wishes of PLwD in a prefecture in central Japan. The

present study showed that the participants expect an enjoyable life and emotional aspects are most important to them. Participants expressed their daily life wishes in a range of elements, including desire of being connected, freedom to decide, involvement in activities, status quo, and self-reliance. The present findings are related to emotional and social factors suggest that the effort to fulfill such wishes could influence their happiness and sadness. This seems inconsistent with earlier studies that identified various aspects of physical health as dominant factors of the quality of life of PLwD. This may be due to the fact that the present study included people with only mild to moderate dementia, and none of them had frailty.

Relationships with family and friends offered the opportunity for meaningful conversations and enjoyable activities. Our findings are consistent with the literature. This was expressed as the most vital need as lack of the presence and company of family members led to depression among participants.

Though the disease trajectory makes the PLwD dependent on others, two consecutive themes in our study, namely freedom to decide and self-reliance, illustrated a great sense of dignity among participants. Inability to take care of oneself and being restricted to have the freedom to decide their activities affected one's feeling of individual respect.

The main strength of this study is the inclusion of PLwD. The study included only people living with mild to moderate dementia who were not institutionalized but lived with the family, and visited the dementia outpatient clinic; therefore, the findings of this study might not apply to the later stages of dementia and who live alone.

Drives to establish a supportive environment and dementia-friendly community for PLwD may fall short if broader dementia contexts are not considered, such as the variations in everyday wishes. Emotional aspect focused care can be achieved through acknowledging the needs of PLwD, especially their desire of being connected with family and others, starting dementia care programs that support the access to take part in enjoyable activities, and securing their sense of dignity.

【Conclusions】

In this study, we explored the everyday wishes of PLwD through their views. The participants expressed a strong wish to live an enjoyable life with dignity. They wanted to stay active and connected with family and friends. They wished for things around them to remain unchanged. Our study highlighted a greater influence of emotional aspects on their everyday wishes. Future research, including people with severe dementia, is required to understand the variations in wishes.