

Having a Say

People with Memory Related Diseases As Customers in Finnish Social and Healthcare Services

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Background and objective

- Two, possibly opposite, trends:
 - 1) The social- and healthcare services in Finland, one of the Nordic welfare countries, are being remodelled: efficiency, regional equality, person-centered care.
 - 2) People with memory related diseases (PwD) are a significant "customer segment" (Appr. 40 % of the patients receiving medical care at home and 75 % of elderly care home inhabitants have a diagnosis of dementia). However, according to the public discourse, the diagnosis of dementia seems often to be a reason to move a person to the outer edge of his/her care.
- We aimed to look at the experiences of people with dementia and their family-members as customers in social- and healthcare services.
 - Exploratory, small scale qualitative study

Data

	Interviewees*	Type	Topic
Phase 1	6 people with dementia, 7 family members	Group discussions	Experiences as customer in social- and healthcare services
Phase 2	4 people with dementia	Structured interviews	Themes raising from the group discussions: PwD as a customer, coordinated services and role of family members

*The interviewees were actively involved with the work of the Alzheimer Society of Finland and had mainly experiences from the services needed at the early stages of dementia.

Analysis

- We grouped the data according to the three themes identified from the group discussions.
- In the analysis, we paid special attention the language and discourse the interviewees used as they were describing their relationship to the social and health care services.

Being a Customer

- The social- and healthcare services played only a small part in the lives of the interviewees.
- They were content in following the guidance of professionals – such as doctors.
 - The “normal”, conventional services were good enough.
- The support of other people in same situation was important in order to find more about available service options – especially in the later stages of the disease.
- The PwD were mentally prepared for a future where they might have less influence over their care and support.

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You can decide about your own matters as long as possible, and maybe even longer with the support from a legal representative. And that I won't be shuffled from one place to another. When I am supposed to choose a place for long term care, I will be able to choose independently where I would stay and the authorities won't just send me somewhere. And that I would have enough time to get familiar with both the public and private long term care facilities, and only after that decide what would be the "memory home" where I would stay. And that the economic decision making would stay in my own hands.

Coordinated Services

- In ideal situation, the support is offered by familial professional and there is no need to actively seek for help.
- Interviewees wished to have tailored services to different needs and wide array of options to choose from.

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There is a new doctor every year. Every time I go, there is a new doctor. If I would go many times in a year there could be the same doctor couple of times. So the doctor has to familiarise him/herself with the life history and what s/he really can remember from that... And so they have to look for consultation from other doctors.

Role of Family-members

- The social- and healthcare services are often relatively fragmented and complex – inclusion of family-members in the care planning brings support to the PwD.
- In the daily life the family-members were crucial enablers of a “normal” life.
- However, the PwD valued their own independence and demanded to be heard in their case.

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A family-member coming with you brings along a sense of safety. I do worry sometimes that I won't remember everything and then it is good to have a family-member with me. And since my short-term memory starts to be poor, so that I might even forget things sometimes.

Conclusions

- According to the prior studies, the possibilities to participate to the planning of your own care diminishes as the disease progresses.
- PwD should be actively involved in choosing the suitable services.
- Practical tools are needed in order to enhance the customer/patient involvement – these could include clear communication strategies, advance directive and feedback procedures.

Thank you!

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