Dementia Study 2022/2023

Part B – Qualitative Study

Needs and requirements of people with dementia and their families

Conducted by Makam Research on behalf of Vienna Social Fund

Dementia Study 2022/2023

The following qualitative study is part of a comprehensive study by Vienna Social Fund which is composed of three parts:

Part A: Research of best practice examples

Part A provides an overview of successful national strategies and measures adopted across Europe to deal with dementia and outlines the experiences in implementing these measures as a knowledge base to support the implementation of Vienna's Dementia Strategy. It also contains research on dementia counselling centres in Austria.

Part B: Qualitative study

Part B illustrates problems and requirements of people with dementia and their (caregiving) relatives and identifies obstacles to the use of services within the existing system.

Part C: Quantitative study

Part C consists of a representative online survey among Vienna's residents (18 years and older) about society's knowledge and perception of the term dementia and the illness it describes and of available offers of information and support.

All part studies serve as a knowledge base that will help to prioritise measures for implementation within the fields of action defined under Vienna's Dementia Strategy. Deductions from the results will be integrated into the evaluation of the nursing and care services of Vienna Social Fund and for strategies to develop new service offers for people with dementia.

Publishing details
Published by: Vienna Social Fund, Guglgasse 7–9, 1030 Vienna,
Tel: 05 05 379, E-mail: kontakt@fsw.at
Responsible for the content: Staff Unit for Reporting and Statistics. Layout and design:
Staff Unit for Reporting and Statistics in cooperation with the Staff Unit for Corporate
Communications. We accept no liability arising from typesetting and printing errors.
Last update: November 2023

Needs and requirements of people with dementia and their families

Study description

From December 2022 to January 2023, Vienna Social Fund undertook a qualitative study on the issue of dementia along the four fields of action of Vienna's Dementia Strategy (awareness raising, participation, living spaces and support offers) to explore requirements and needs from the perspective of people living with dementia and their families and friends.

The study consisted of 10 narrative biographical interviews conducted with people who have dementia (if required, they were accompanied by relatives or friends) and two focus groups with caregiving and non-caregiving family members. The goal is to use their experiences to tailor support offers for people with dementia and their (caregiving) family members as far as possible to their requirements and to develop them further.

The market and social research institute MAKAM Research GmbH was tasked with carrying out the project.

Research question

What needs and requirements do people with dementia and their caregiving and non-caregiving relatives have within the Vienna Dementia Strategy's 4 fields of action?

Key findings – people with dementia

Awareness raising

The way society deals with dementia is perceived as lacking in empathy and seems to be characterised by “polite disinterest”.

It is a long way until people get a diagnosis; often they are diagnosed by accident.

Sometimes the diagnosis is **accepted**, sometimes it is **denied** (symptoms are “normalised” as by-products of ageing).

People’s attitude towards their diagnosis determines how they cope with the situation and if they seek information or support and use medical or therapeutic help.

> *“Acceptance, not because you have to, but maybe just to be polite.” (m, person with dementia)*

> *“They have told me not to worry and have said, well, at your age – I‘m 72 now, and I was 65 or 66 then – it’s quite normal that you don’t remember things. But then it got gradually worse.” (m, person with dementia)*

> *“I’ve always had high blood pressure and I received treatment for that.” (f, person with dementia)*

> *„And they simply don’t want to accept that and my daughter tells my grand-daughter, ‘Granny has dementia and cannot do anything anymore’.” (f, person with dementia)*

Participation

Depending on people’s biography (hobbies, family size, membership in associations etc.), being faced with dementia on the one hand may lead to **withdrawal** from social interactions, while on the other it may give rise to **coping strategies** (make sense of the situation by engaging in new hobbies, volunteer work etc.) or even lead to both.

Loneliness is a key issue (withdrawal from friends and family).

Participation in **everyday life** often requires the cognitive skills of healthy adults.

> *“Well, I have three cats at home and spending time with them is my greatest pleasure. And in the evening, when I can say that I’ve done everything I’ve planned to do – usually I write everything I need to do down on a piece of paper, and I look at the notes in the evening and [when] I’ve got everything done, this also makes me happy.” (f, person with dementia)*

> *“He won’t give me any reasonable answer anyway, or whatever. And it also depends on how severe the dementia is. There are people you can hardly talk to.” (m, person with dementia)*

> *“I did not want to become a burden on them. I did not want to have a conflict with anybody. I told myself that I have no other choice than to keep quiet about it. And keeping quiet is expensive, mentally, as you lose your social contacts and social activities. This is a tremendous burden on the brain and on the mind […].” (m, person with dementia)*

> *“He has just had a child himself; you can’t do that. An absolutely lovely family. But I withdraw from social activities. It’s my fault. He has invited me once and we had a very nice time together.” (f, person with dementia)*

Living spaces

The terms **“dementia-friendly Vienna”/“dementia-friendly districts”** are hardly known.

“I don’t know, maybe that you help people with dementia.” (m, person with dementia)

“People will get used to it over time.” (f, person with dementia)

Support offers

3 types of **support offers:**

- preventive activities for memory training or creative activities
- family members (especially women are socialised into the role of helpers)
- day centres (praised by all respondents & their families)

Information sources about dementia include

- family members
- the internet
- members of the healthcare system (esp. GPs, hospital discharge management and day centres)

People visit day centres mainly to **ease the burden on family members** and **make use of the various activities offered there** (outings, therapies, social contacts)**.**

Day centres support visitors in coping with their diagnosis and in developing new roles and potentials.

“[...] a very friendly one, I call [him [= his son]] brother. (laughs) [...] he’s the one I love most in this world.” (m, patient with dementia)

“[...] my daughter has found out about it and has organised it. She is a professional midwife. She has certain insights and contacts in the medical sector.” (f, person with dementia)

“I’m here at the day centre, because I was all alone at home. My three daughters all have a job, they also work in the social sector. And being lonely is the most difficult part for us old people, that’s what I also hear from my peers. And that’s why I love to visit the day centre. I’m grateful that there is something like that.” (f, person with dementia)

“I move around, I wash the dishes and put them away and I help [name] to peg the washing on the line. I always stay busy and I also go grocery shopping with her. I consciously make sure that I always do or achieve something myself. I also do a lot of sudokus or cross-word puzzles.” (f, person with dementia)

“To the Vienna Social Fund. I mean, the things I have learned from my colleague, who was a coach, and they have given me a lot of support – and social workers and they have all helped me.” (f, person with dementia)

“My best neighbourhood is the day centre.” (f, person with dementia)

Key findings – family members

> *"[...] for a long time, my father did not accept that something was wrong with my mother." (f, non-caregiving family member)*

Awareness raising

Before getting the diagnosis, dementia processes are **not properly interpreted** – e.g. because they are downplayed or they are not recognised as such.

After the diagnosis, family members are overwhelmed both emotionally and by organisational and administrative tasks.

Family members want **society to be sensitised** on how to deal with people who have dementia. They want dementia to be **destigmatised** and the issue to be integrated into healthcare education and training and portrayed positively in the media (e.g. TV shows).

The **behaviour** of people with dementia is **not properly understood** (e.g. aggressions/anger).

> *"[...] Yes, it's kind of a mix of feeling overwhelmed by administrative tasks and being mentally overwhelmed." (f, non-caregiving family*

> *"That you simply know how to talk to such people; that you keep in mind that it might be [dementia]." (f, non-caregiving family member)*

> *"The main problem was the complete isolation, very aggressive, fending off everything." (m, non-caregiving family*

> *"I also stopped working one year earlier than planned, because she [= mother who has dementia] was no longer able to cope with her everyday life." (f, caregiving family member)*

Participation

Some family members need to make **drastic adaptations** (quit their jobs, put their own needs aside).

Social participation should be promoted through the **organisation of joint activities** for people with dementia and their family members.

> *"[...] I wouldn't have thought one or two years ago that we would come together again like that. That I would show him things which I'm interested in and that this would make him somehow participate socially in the city." (f, caregiving family member)*

Living spaces

The terms **“dementia-friendly”/“dementia-friendly districts” are hardly known** and sometimes seen negatively, as they are understood to imply a stigmatisation and spatial separation of people with dementia.

A more positive connotation of the term **“dementia-friendly”** by generating positive marketing and publicity.

GPs are often the first contacts, but they are rated differently due to their different levels of dementia knowledge.

> *“[…] But it should be more commonly known what it [dementia-friendly] means.” (f, non-caregiving family member)*

> *“It is not depression. Granny has always suffered from depression. Then she [GP] suggested to get an MRI scan to exclude (unintelligible) dementia, and then it showed quite quickly that, yes, it actually is dementia.” (f, non-caregiving family member)*

Support offers

Most family members use the internet for their **own research,** which requires a great amount of time and effort due to the **wealth of information** available there.

Mobile services (home help, companionship care, home nursing and visiting services) are primarily seen as helping with small tasks of daily living, but are hardly mentioned otherwise.

The situation **cannot be handled without the support** of professional carers or other family members.

The most popular **support services** used – depending on the stage of dementia – include **day centres** and **care & nursing homes.**

External support from home helpers and 24-hour carers is also used, but is rated ambivalently.

Main requirements of (non-)caregiving family members include:

- Learning how to communicate and deal with people with dementia
- Care skills
- Psychosocial support for family members
- Support with bureaucracy
- Information on treatment methods and medication

> *“Hardly any [information]. And that’s the main problem.” (m, caregiving family member)*

> *“That’s right, yes, if you’ve got a large family. Not that it’s easy for us, but it is easier.” (m, caregiving family members)*

> *“Well, I think, my mother would rather refuse home help services, because her neighbour has had some bad experiences.” (f, caregiving family member)*

> *“In particular, they also have to assist with personal hygiene tasks.” (f, caregiving family member)*

> *“[…] the day centre we use, [they] are very, very committed. And they are very friendly, offer a lot of support and they give me every piece of information they think I might find useful.” (f, caregiving family member)*

> *“ […] These are little tricks which the nurses use, they have all received professional training, and you can [get] a book, you can read it online. There is a thin book and you learn how to communicate and we have learned it from the nurses there.” (f, non-caregiving family member)*

Methodology and study design

	Qualitative study		
Survey period	December 2022 – January 2023		
Method	Focus groups with family members Individual interviews with people with dementia		
Method of analysis	Content analysis		
Family members	7 caregiving family members		
	2 partners 4 children 1 grandchild	4 women 3 men	Average attendance allowance level: 3.3 Average age: 56 years
	7 non-caregiving family members		
	1 partner 5 children 1 grandchild	4 women 3 men	Average attendance allowance level: 4.5 Average age: 59 years
People with dementia	10 people with dementia		
	7 people with beginning/slight dementia 3 people with middle stage dementia	6 women 4 men	Average age: 82 years