

Report on the Dementia Research Forum 2019

Involvement of People Living with Dementia in Research on Cognitive Ageing

On 19 and 20 September 2019, the first Dementia Research Forum took place on the Belval campus. People with dementia were invited to the university to discuss the research questions of the CRISP project with us and to advise us on the publication of our research results. The idea of giving people affected by dementia a voice in research projects is already being successfully implemented in other countries such as the UK.

In the following I will first present some general information, then I will summarize the contributions of the participants.



The group of the first day.

The Dementia Research Forum is intended to give people living with dementia the opportunity to get to know our research, but even more important is that **people with dementia from their viewpoint as experts in the disease** – after all, they live with it – advise us researchers on how we can better explain our research results to the public. The participants had the opportunity to bring along accompanying persons, which is

why the group of the first day consisted of patients, relatives and a psychologist from the health sector. Since, during the preparation of the event, relatives of people living with dementia had also shown great interest, a second session was planned and carried out for the relatives.

The aim of the CRISP project at the University of Luxembourg is, put generally, to better understand the **risk of dementia** throughout life. As a first research objective, we investigate the school and social conditions for building up cognitive reserve, which may play out in differential cognitive functioning and aging at older ages. A second research objective is to investigate the extent to which individual factors, e.g. exercise, can influence the risk of dementia. The CRISP project runs for five years and is funded by the European Research Council (ERC) with 1.15 million euros (agreement no. 803239). The project is accompanied by an ethicist.

After the approximately two-hour morning discussions, each of the two sessions of the Dementia Research Forum ended with a joint lunch and a short tour of the campus. All participants received a certificate of participation in the Dementia Research Forum.



The certificate of the Dementia Research Forum 2019.

In the following I summarize the contributions of the two sessions. I mention the instances in which there were differences of opinions of people living with dementia and close relatives and caregivers.

The research questions of the project were explained and discussed. There was also a great need for discussion with regard to the planning (*co-creation*) of the **public conference of the project in 2021**, at which relevant information will be disseminated to the public that is considered important in the national context. The envisaged participants of this conference will be stakeholders, representatives of the relevant organizations and ministries, and affected persons and their relatives.

The first research question of the CRISP project aims to investigate whether unequal educational opportunities in early life can lead to differential building up cognitive reserve depending on educational context, which can possibly explain differences in cognitive performance at older ages. This question was discussed with regard to the involvement of parents, i.e. the extent to which parents would additionally pursue valuable extracurricular activities with the children, such as reading to them. Participants stressed **the importance of parental attitudes** in relation to the ascribed value of higher education.

A second research question deals with the fact that **inequalities based on gender** could have led to disadvantages for women from earlier birth cohorts in school and working life, which would lead to lower cognitive reserve and poorer cognitive performance in women in later life. The participants commented that this research question was relevant and unreservedly valid. It was judged indeed very important to look at the norms and role expectations of women and men in former decades and to draw conclusions about the possibly unequal opportunities that existed in school and working life for men and women at the time.

A third research question deals with the **long-term risk factors** for cognitive decline and dementia, e.g. sports activities. One person living with dementia said that **research findings on population level are not always accurate in individual cases**, for example the findings that physical exercise helps to delay dementia. He himself had always done a lot of sport and physical exercise, and still had memory problems (but perhaps he would have gotten the problems earlier without sport, he conceded). The other participants agreed. The participants emphasized that physical activity in earlier decades, e.g. the work on a farm, had also been strenuous, but had not been called "sports". Thus, possibly questions about physical exertion could be misunderstood in studies. I was able to refute this objection at least for some of the datasets, e.g., the *Survey of Health, Ageing and Retirement in Europe*, where the question on physical vigorous activity includes both exercise and/or activities in the household and garden.

One participant expressed appreciation of the fact that research on dementia is considered important and funded at the European level. The research project would be evidence of the ascribed value of involving and co-creating research together with people living with dementia.

We discussed and clarified the different forms of dementia at request of the participants. Today dementia is considered as a range of conditions characterized by memory impairment. Alzheimer's dementia is the most common form, initially characterized by memory disorders, such as not finding your way home or forgetting recent events. How severe the memory problems are can change within hours or even minutes.

A participant living with dementia had difficulty to remember their first place of residence. A few minutes later, however, he was able to recall his former address. He explained that one often only needed a little time for him to remember these details.

A woman who lives with dementia found it very important to **come together and exchange with other affected people**, e.g. in the accompanied support group of the Association Luxembourg Alzheimer (ala). Since people living with dementia can still do

some things, but not as well as healthy people - for example sewing, bowling, training on fitness equipment - it helps to do these activities with other affected people. Usually it would be great fun to do the activities one is still able to do.

The participants found that more people should **know about dementia** in their everyday lives, e.g. employees in supermarkets, bus drivers or train staff. A woman living with dementia said that, first, people should know that there are different forms of dementia. Then there is the initial stage in which one can still do a lot, but in between "draws a blank" and needs help. Even younger people – she herself was in her early 50s when she was diagnosed – can already have the disease. It would be desirable to be treated with respect and understanding in everyday life, living with or without dementia.

One affected person showed a card which the participants of the national Alzheimer's Association (ala) accompanied support group developed. The card explains in a few words that the owner of the card has memory problems and may need help. This help could be, for example, a short spatial orientation in the train station or shopping at the supermarket checkout.

Participants mentioned that it would be nice to have even more **open structures or meeting places** where affected persons could go without registering if they want to talk to others or just want to leave the house. It would also be important to have more structures for **younger affected persons**, as, at the moment, affected persons in the 50s are in the same structures together with affected persons who are 20 or 30 years older. That would not fit well.

The participants who live with dementia themselves, said that, **in hospitals, many people do not know about dementia**. Also, the process of getting a diagnosis of dementia was difficult for some of them: Either the diagnosis was not communicated at all to them personally. In other instances, on the contrary, the diagnosis was

communicated like a death sentence, even if after onset of dementia it would still be possible to live a good life for some time.

Caregivers of people living with dementia were worried about **what would happen in an emergency** if they themselves were not available, for instance, when they had to go to the hospital. It would be recommended to have a nationwide system, such as an emergency box in the refrigerator. Here where the most important health relevant information about the person living with dementia could be found. The firefighters/emergency paramedics could check this information directly in an emergency situation even in cases when the main caregiver could not be around.

One relative said that it makes a big difference whether you are "in the first or second row" when someone in the family falls ill with dementia. One is much more burdened and challenged when **one is the main responsible person** for the health and well-being of the person living with dementia. It would be very helpful to exchange experiences with others and to laugh together if everything became too much.

The relatives said that they would have wanted to **know better what to expect** in the progress of the worsening of the disease. They would have liked to have had some kind of list to prepare them for things that could happen, even if it might be frightening.

For example, there should always be **spare keys**, as keys are often lost. A female caregiver described her **guilty conscience** when she could no longer allow her husband to drive. Previously, after her husband had driven the car, the exterior mirrors were damaged several times "for unknown reasons" according to him, so she knew he was not aware of his driving problems. It would also be difficult to cope if the affected person had **no insight into the illness** and resisted restrictions. In her case, in the end her own health was at risk due to increasing changes in behavior of her husband, such as locking her out. Due to her husband's lack of insight, only clear statements by the neurologist had helped her and the children to provide her husband with appropriate care and to accommodate him without endangering himself or others.

Caregivers of persons living with dementia advised that one would need to try to find out what the affected person could still do, e.g. if they could still understand written words, since sometimes persons living with the disease would not notice worsening of their abilities themselves.

The relatives noted that it was **difficult to figure out** the point in time when the person with dementia was **no longer able to live alone**. This focus on possible restrictions is understandable from the point of view of the relatives, since they bear responsibility for the affected person or at least assume it. However, the participants who themselves are living with dementia argued that the focus had to be much more on resources, i.e., what **one could still do**, instead of just looking at the deficits.

The relatives said that one was **often alone with one's own emotions**, e.g. feelings of **guilt, loneliness or anger, but also fear for the well-being of the children**. After all, dementia would be partly hereditary and the lack of a drug that can prevent or delay the onset of dementia would be frightening. A good environment and help from the doctors but also from other relatives would be very important.

The offers of the **Association Luxembourg Alzheimer (ala)** were considered a great help for the relatives. Relatives should also know that it is difficult for those affected to eat regularly, as sensations, such as feelings of hunger, become less reliable with progressing dementia. Especially those affected who have had traumatic experiences during and after the war may hide food or money or feel threatened in their own home.

The exchange between research and practice was mentioned as an important component of the Dementia Research Forum, as was the fact that "research" is interested in the reality of the lives of those living with dementia.

We would like to thank all participants once again for their help!

The next Dementia Research Forum will take place in one year. We would be delighted to see many of you and many new faces at the Belval campus for the next meeting.

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