

Everyday Experiences of People Living with Mild Cognitive Impairment or Dementia: A Scoping Review

Short version jointly written by George Rook and Jacoba Huizenga

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Brief foreword by George Rook, expert by experience:

This research paper is important because it brings together findings in 58 research projects that evidence the ways in which people experience living with a diagnosis of dementia, or MCI.

Post diagnosis support has hitherto been largely based on what health and care professionals believe people living with dementia (like me) or MCI need. Many of us find these approaches demeaning or meaningless, and they do not address our real experiences and needs. In addition, Dementia Friendly Communities is a concept based largely on the perceptions of people in positions of power rather than people, living with dementia or MCI.

So this new research at last identifies our reality and our actual needs, which revolve around being included in normal social life, as adults.

We do not want to be dis-abled by professionals who think they know what is good for us. We want to be en-abled to live as well as we can or we choose, as full members of our communities.

I urge all health and care professionals to read this research paper and to make sure that their work reflects the findings.

Above all, ask us what we want. Do things with us, not to us.

[George Rook](#) lives as he chooses with young onset dementia. He is an activist and campaigner, including for Admiral Nurses and DEEP groups. He is part of the [Dementia Enquirers](#) (a DEEP project). This project aims to develop a new approach to research, that is led and controlled by people with dementia.

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Summary

Increasing attention has been paid to the 'voice' of people living with mild cognitive impairment (MCI) or dementia, but there is a lack of clarity about how everyday life is perceived from this insider's perspective.

This study aimed to explore the everyday life experiences, challenges and facilitators of individuals with MCI and dementia living at home.

This study reviewed 58 research papers published between 2011 and 2021. Analysis looked at descriptive findings in these papers, rather than numerical data.

Findings were described in seven aspects of everyday life:

- experiences related to the condition,

- self,

- relationships,

- activities,

- environment,

- health and social care and

- public opinions.

The results show many disruptions and losses in everyday life and how people try to live with these changes. In all areas of everyday life, people show a deep desire to have relationships with other people, stay engaged through participation in activities and have a sense of belonging in the community.

Findings

1. Dementia

a. Receiving the diagnosis

Participants in these studies responded differently to receiving the diagnosis.

The first response concerned shock, confusion, sadness and fear.

Respondents found it difficult to accommodate the news.

Participants felt alone as it was difficult to accept that there was no cure for the disease.

Participants were afraid of becoming 'second-class citizens' who others would look down on.

Some participants did not accept the diagnosis or denied the outcome.

After receiving the dementia diagnosis, participants said one dilemma they faced was whether to disclose their diagnosis to others. They were afraid that people's attitudes toward them would change.

The advantages of being open were receiving positive responses, strengthening current relationships, being able to tell people about the difficulties they faced, and raising broader awareness of dementia.

The diagnosis was described as useful, as it explained their behaviour and the feeling that something was wrong.

b. Changes and dealing with changes

One broad category of change refers to cognitive decline, such as concentration difficulties and forgetting daily events, names of people and places, people's faces, birthdays and retrieving stored items. Participants were aware that their ability to learn had decreased; and therefore, newer tasks were harder to remember.

There were also challenges in communication: participants did not find the right words, repeated themselves in conversations, forgot what they wanted to say, or found it difficult to follow conversations as their focus was reduced.

Compensatory strategies, such as taking more time, repeating, trying to think systematically and making notes are mentioned. However, the strategies were not always effective; for example, it could be difficult to find the notes again. Several tools have been used, such as calendars, whiteboards and technical aids, sometimes with the support of relatives.

Some participants made a specific effort to keep the brain active by reading and memorising poems. However, when there was no improvement, they experienced frustration and felt that they were losing their control.

Coping strategies are mentioned in many studies, including trying to ignore or hide difficulties, using humour, using creative expressions, avoiding stress, maintaining daily structure, staying active, focusing on what they can still do, finding meaningful ways to (re)engage and seeking social and religious support.

In several of these studies, a shift in attitude to what was important for them in life is described, for example by paying more attention to 'little things' and living in the 'now'. One of the participants voiced this as followed: "Take it as it is and live today".

c. Future living with dementia

Several participants mention a deep sense of uncertainty about the future, associated with anticipated loss and worries about the trajectory of the disease.

Some were able to face this and remained positive, while others found this very difficult and constantly felt a shadow of fear.

One study reports that for participants with young-onset dementia the uncertainty could be more difficult to endure than dementia itself .

Some participants proactively made plans and took control by, for example, moving to a new dwelling or deciding whom to leave their money or inheritance.

2. Sense of Self

Many of the studies include content regarding the sense of self. These experiences can be divided into three subcategories:

self-evaluations

emotions and

sense of body.

a. Self-evaluations

In a few studies participants expressed that after diagnosis they felt like different people, or they were concerned that they would turn into a different person.

Nonetheless, several studies stress that in essence they were still the same. For example, in one of the studies a participant expressed: "I'm still me, or at least a version of me".

Losing abilities and memories were a threat to their identity which could lead to a sense of self-doubt, uncertainty, and uselessness. As a result of losing competencies, participants also experienced a loss of social roles.

The importance of remaining independent and making one's own decisions for as long as possible has been frequently reported.

Three supportive strategies are identified. Firstly, through emphasizing their worth by mentioning positive traits or their significance to others.

Secondly, some studies report that biographical places, events and personal biographies were supportive of identity, for example, a neighbourhood where participants had lived for a long time.

Thirdly, being able to make a meaningful contribution, remaining useful and being valued emerged as important. Some participants regained this by becoming experts by experience.

b. Emotions

In some studies participants felt that they changed emotionally, as they sometimes lost control of their emotional reactions such as crying, anger or laughter. This could also lead to feelings of shame.

In response to disruptions in daily life and failures, such as home accidents, negative emotions such as frustration, anger, depression and for some even despair are described.

Another frequently shared emotion, was increasing fear and uncertainty when going outside, or the fear of losing control related to further cognitive decline.

c. Sense of body

Several studies describe participants feeling tired or exhausted, as coping with their situation costs a lot of energy.

Some studies report a loss of initiative, lack of desire and apathy, and some other studies mention trouble with sleeping or maintaining a day-night sleeping routine. The rhythm of daily life seemed to slow down, and body movements and pace became slower.

3. Relationships

Relationships are generally described as important sources of connection and support. The absence of relationships, especially for participants living alone, led to feelings of loneliness, which worsened after the diagnosis of dementia. This sense of loneliness could even be existential, as quoted by one participant: "So I feel . . . alone in the whole world sometimes. Although I know that I'm not, that's what I feel like".

One study report that reminiscing helped overcome feelings of loneliness.

a. Relationship with partner and family

Social support from partners is important. Support could be practical, such as driving or helping to remember things, and emotional during times of frustration.

In some studies participants stated that they felt dependent on their partner or anxious when their partner was not around.

Changes in sexual life are only mentioned once.

Family is described as an important source of feeling connected and supported. Family members can also be advocates to overcome challenges in society.

The importance of reciprocity in family relationships is highlighted in several studies, for example by helping family members or spending time with their grandchildren.

Challenges in familial relationships have also been reported, most frequently the experience of family members being too protective and disempowering by questioning their capabilities.

Participants reported feeling that they had lost their meaningful role within their family.

Participants emphasised their concerns about being a burden to their family.

Other experiences described are difficulties relating to physical distance, avoidance by family members from talking about dementia, and struggles of their children to accept or believe the disease.

b. Relationships with friends

Many participants reported about relationships with friends.

It is important to feel connected with close friends without feeling stigmatised.

Some participants had good contact with existing networks. Others tried to find new contacts, which could be complicated after moving into a new neighbourhood.

Internet technology could bridge long distances.

In a few studies participants preferred that people visit them at home instead of visiting others.

A lot of participants appreciated gaining new friends through dementia-specific groups, both in person and online. They experienced these relationships as more equal, supporting and empowering, as it implied an 'unspoken understanding', which felt like a form of relief.

In a few studies with participants living alone, they reported that they needed to put an effort into maintaining social contacts, some with the help of their children.

Several studies report that participants had lost their friends. Participants shared that they did not feel understood in their friendships when sharing their difficulties because of relativizing comments, such as "Oh yes, I forget things too" or avoidance of the issue.

Some participants with MCI chose to withdraw themselves as a way to avoid embarrassment due to their mistakes or because of negative peer responses.

c. Relationships in the wider community

Relationships in the wider community are important. Several studies describe how neighbours provided practical support, such as the management of household waste, looking after pets and gardens, or simply having brief social encounters.

Some participants informed their neighbours about the illness which provided an understanding and a sense of security.

Several studies describe the neighbourhood as a place for spontaneous encounters, especially if participants lived there for a long time. For example, they referred to encounters with staff in shops or being greeted by passers-by.

Participants actively sought possibilities for connection, such as sitting on a bench in the centre of the neighbourhood or walking their dog.

One study also mentions acts of kindness by people in the neighbourhood, such as when they got lost.

Religious communities provided a sense of community.

Challenges in the community are also reported, namely the experience that people had a 'fear' surrounding dementia and that they felt anxious about making mistakes in public, for example when withdrawing cash or afraid of becoming a victim of crime.

4. Activities

Participants shared the importance of staying engaged in daily life through participation in activities, which provided a sense of meaningfulness, independence and belonging. However, the progressive reduction in functioning could lead to inactivity and loss of meaning in activities. Activities can be divided into activities of daily living and participation.

a. Activities of daily living

Some participants felt still being capable of self-care activities, while other participants reported challenges, such as forgetting medication, or forgetting to eat and drink.

The assistance of relatives, or tools such as schedules and notes is reported to be supportive.

Several participants expressed that they experienced taking care of household chores, such as cooking, cleaning and taking care of pets, as meaningful. By doing these activities they maintained their routines, and sensed reciprocity and responsibility.

Many studies describe that the household became increasingly difficult to manage and tasks took longer to complete due to forgetting tasks and where things were put, as well as difficulty in recognising how to use everyday objects. Challenges with cooking in particular are mentioned and some participants consequently stopped for safety reasons.

Some, however, found practical solutions such as timers, preparing uncomplicated food or using meals-on-wheel services.

Regarding administrative tasks, such as paying bills and organising mail, some participants felt that they lost control over it. For example, they were worried about doing something wrong, so they checked their work over and over.

The activities of daily living outside, such as getting out of the house or going to a shop, are described as important for participants. This provided a sense of independence and being connected to, and part of society, which in turn prevented feelings of loneliness.

Challenges with routine activities outside, such as the effort it takes to prepare for going outside, activities that are experienced as 'too busy', dealing with money outside, keeping an overview of the actions that make up an activity, and not getting lost are mentioned.

In one study participants mentioned the JAM ('just a minute') card as useful, to show when they need 'just a minute'.

In several studies participants adapted their driving routines or had to give up driving for safety reasons. Participants who had lost their driver's license experienced this as a loss of their valued freedom, which also impacted their participation in activities.

Experiences with public transport were different: in a few studies participants were happy to use it nearby, but in a lot studies participants felt overwhelmed by the transport system or were afraid to get lost, and therefore only travel accompanied.

b. Participation

Several participants who were still employed, sometimes in an adapted job, experienced increasing difficulties with more cognitively demanding aspects of their work.

Participants in a few studies felt employers forced them to give up their work. Participants who had to quit working felt a deep sense of loss and strongly missed their daily structure, engagement, role in life and contact with colleagues.

In one study a participant expressed: "If we go to our relative's house, I see how others are active. This breaks my heart . . . [crying] . . . I don't act like an active person: I who could move mountains! When I was employed, I worked from 8 am until 12 midnight; now, why should I be like this? Why?".

Volunteering provided participants with a new way of contributing to and connecting with the community. A specific way of meaningful volunteering was dementia advocacy, such as speaking at dementia conferences, using Twitter and joining research projects.

Several studies describe leisure activities as social, cognitive and physical engagement, for experiencing meaningful days and reducing stress.

Participants wanted to focus on activities they had always done for as long as possible, and discover new activities.

A wide range of leisure activities are mentioned: watching TV, reading books, gardening, creative and cultural activities such as painting and singing in a choir and physical activities such as walking and doing exercises.

In some studies participants stressed that they liked to learn new things, either individually or with other people with dementia, such as learning to write, knit or use a tablet to play online games.

At the same time, in many studies people reported that they had to reconcile themselves with downsizing or giving up hobbies and activities, for example because of difficulties in concentration, memory problems or physical complaints.

Other specific hindrances described are the feeling of being excluded, the absence of group activities, or difficulty to pay fees for activities. Loss of activities can lead to isolation.

5. Environment

Information regarding the (physical) environment is described in several studies. A few studies reported the need for a sense of familiarity with spaces and routines which enabled belonging.

a. At home

Participants most often stayed at home, and this sense of security, where things were familiar, became increasingly important. Participants wanted the home to be safe to navigate, including at night, as well as cosy and surrounded with cherished belongings.

Days at home could be monotonous and isolated. Looking out through their window or from their balcony to see children or other people passing by gave a sense of connection to the world outside.

Some studies describe the transition of moving to a new, smaller house as difficult for various reasons, such as it feeling like a too daunting task, or not remembering where things were in the new house.

b. Public space

Several studies describe that to feel safe without getting lost, participants preferred familiar spaces close to their home and the routine of going to the same recognisable places by using the same path.

Some participants actively avoided difficult traffic situations and roads that were difficult to walk on, sometimes also because of weather conditions.

Changes in the environment, such as roadworks or unexpected changes of their perception could result in unfamiliarity and confusion. At these moments people tried to regain familiarity by seeking reference points such as bridges.

Road signs and maps can be difficult to understand.

Crowded places and noise levels could create feelings of insecurity, and also areas where there are no people in sight generated these feelings.

One study mentions participants who gradually avoided going outside because they were afraid of falling.

Going outside to feel connected with nature is mentioned in five studies, for instance, by walking in parks, hearing birds, meeting animals and seeing trees and flowers.

6. Experiences with Healthcare and Social Services

On the one hand a few studies mention the importance of professional support to overcome challenges.

On the other hand in several studies participants shared that post-diagnostic support did not match their needs.

Participants wanted to learn more about their condition, experienced obstacles in the system, and sometimes overprotection.

Participants with young-onset dementia and those living alone missed tailored services.

a. Experiences with healthcare

Some describe general practitioners and neurologists taking the time to talk with them and their families.

In one study participants experienced a lack of information. In other studies participants found that the information was much too biomedical, while negative information induced feelings of incompetence. "It took me a few months myself to realise, actually dementia isn't a death sentence and there is plenty of fun still to be had".

In a few studies participants shared positive experiences with home care services, and especially participants living alone enjoyed it when caregivers took time to talk or walk. These visits could be the only social contact during the day.

Other participants shared difficulties about the care relationship. Caregivers were too task-oriented, while they longed for social interaction. Caregivers took over their autonomy, or there were too many different caregivers.

Specific challenges mentioned were struggles with the telecare alarm service that did not function adequately and the desire that homecare workers monitored mealtimes. Some participants were not aware of, or could not remember, the reason caregivers visited them, so they suggested that caregivers wrote down when they came and why.

b. Experiences with social services

Individual social work is scarcely mentioned. In only one study a participant talked about a support contact person who offered assistance with everyday tasks, stimulated activities and provided company. This participant felt strengthened, and this contact was even a substitute for old friends.

Some participants with young-onset dementia reported inadequate support for financial problems after losing their jobs. In other studies support groups are mentioned, either tailored to early-stage memory loss or to people with young onset dementia. These programs provided concrete strategies and support for developing a sense of independence and empowerment.

In several studies participants shared their experiences with activity groups of community centres, dementia cafés, day centres and in nursing homes. Participants mentioned positive experiences such as feeling enabled to perform activities, having fun in a safe environment, prevention of loneliness and improvement of the spousal relationship by spending time apart.

A specific program was developed at a secondary school where participants with dementia attended an adult school, which provided a place to learn new skills and engage in a wider society.

Negative experiences regarding group activities are also mentioned, such as a lack of day centres close by, problems affording the required fee, no accommodation for personal interests and capacities and problems with transportation.

7. Public Opinions

Participants felt frustrated with the misconceptions of society about what dementia is and the perceived disabilities.

They experienced the stigma of being incapable of anything, as expressed by one of the participants: "When you've got Alzheimer's, everyone thinks that one is just destroyed, which is completely wrong".

Negative media portrayals of disempowered people, and the use of obstructive language such as 'demented' and 'sufferer' were extremely upsetting.

Participants wanted dementia to be normalised in the community.

In addition, the media could play a huge role in positively influencing people's views that people living with dementia can have a good life.

Some participants used blogs or Twitter to challenge stigma, raise social awareness, achieve equality and give hope to others with dementia.

One of the participants expressed: "People don't realise the positive side, that you can still live, and you can live for quite a long time, depending on the dementia. So, I use it to educate and to change minds about things". Unfortunately, people were also exposed to being trolled on Twitter, or to receiving tweets questioning their diagnosis.

Conclusion

The results show many disruptions and losses in everyday life and how people try to live with these changes. In all areas of everyday life, people show a deep desire to have relationships with other people, stay engaged through participation in activities and have a sense of belonging in the community.