

Summary

What helps family caregivers of people living with mild-to-moderate dementia to 'live well'? Findings from the IDEAL study

Family members and friends (here we use the term 'family caregivers' to cover both) provide vital unpaid care and support for people with dementia living in the community. Providing care and support in this way brings both rewards and challenges. We know that family caregivers of people with dementia experience poorer quality of life, satisfaction with life, and well-being than both the general population and family caregivers of people with other kinds of health problems, so it is especially important to understand what helps family caregivers of people with dementia to 'live well' and use this understanding to improve support for family caregivers.

Previous research has looked at various aspects of family caregivers' experiences and the influence these have on how well caregivers are doing, but often just a few aspects have been studied in isolation, and with fairly small numbers of caregivers. This means it is hard to know which aspects are most important. Also, when studying these influences, researchers have focused on their impact on either quality of life, satisfaction with life, or well-being. As these things are similar but not exactly the same, it is difficult to compare results from different studies.

We decided to look at as many aspects of family caregivers' experience as possible all together, to see which are most relevant to whether or not caregivers are 'living well'. Rather than just choosing one way of measuring whether caregivers are living well, we decided to use all three ways and include caregivers' perceptions of their quality of life, satisfaction with life and well-being in our evaluation.

We used information provided by 1283 family caregivers taking part in the IDEAL study. These were family caregivers of people with mild-to-moderate dementia living at home in the community. About four out of five were spouses or partners of the person with dementia and the rest were mainly grown-up children of the person with dementia. Just over two-thirds were women.

Family caregivers rated their own quality of life, satisfaction with life and well-being, and we used statistical methods to combine these ratings into one 'living well' score. From the other information caregivers gave us, we were able to select 48 aspects of their experience and group these into 7 domains:

- Psychological characteristics and psychological health (e.g. personality characteristics, optimism, self-esteem, loneliness and depression).
- Physical fitness and physical health (e.g. physical activity, lifestyle and health conditions).
- Experiencing caregiving (e.g. stress and coping).
- Capitals, assets and resources (e.g. social resources, social networks, and participation in social and cultural activities).
- Social location (e.g. social class and perceived social standing).
- Relationship with the person with dementia (quality of the current and past relationship).
- Managing everyday life with dementia (e.g. perceived severity of and distress at the symptoms of the person with dementia).

For each domain, we used statistical methods to identify which aspects of caregivers' experience were associated with their 'living well' scores. These aspects were included in the next stage of the analysis, where we developed a model showing how strongly each domain was related to caregivers' 'living well' scores.

We found that Psychological characteristics and psychological health was most strongly related to living well, followed by Physical fitness and physical health and Experiencing caregiving. Capitals, assets and resources and Relationship were also related, but less strongly. Social location and Managing everyday life with dementia were not related to living well.

We only included information from caregivers who were supporting someone with mild-to-moderate dementia living at home, so the picture may be different for caregivers who are supporting a person with more advanced dementia, or who is living in a care home or nursing home. Almost all of the caregivers had a white British background, and caregivers with other backgrounds may have different experiences.

These findings provide new evidence about what enables family caregivers of people with mild-to-moderate dementia to 'live well'. How well you fare as a caregiver is not about your status in society and is not directly connected to the types of difficulties or symptoms that the person with dementia is experiencing, although a good, close relationship does help. Your mental health and your outlook on life are the most important things, alongside being able to deal with the challenging aspects of caregiving such as managing stress, and your physical health. Having a strong and supportive social network, and participating in social and community activities, is also valuable.

The findings show the importance of supporting family caregivers' mental and physical health and their ability to develop positive coping strategies and manage stress, and enabling them to maintain social contact and participate in social activities.