

Summary

A comprehensive model of factors associated with subjective perceptions of living well with dementia: findings from the IDEAL study

The IDEAL programme is a large research project that aims to find out what helps people to ‘live well’ with dementia and how this changes over time.

This study used the information provided by the 1550 people living with dementia in England, Scotland and Wales who took part in the first stage of the IDEAL programme. They rated their quality of life, satisfaction with life and well-being, and we combined this information into an overall ‘living well’ score.

We then wanted to see what aspects of people’s lives are linked to being able to ‘live well’. The participants rated many aspects of their lives and we grouped these together into five domains:

- Psychological characteristics and psychological health included things like personality, optimism, self-esteem, loneliness and mood.
- Physical fitness and physical health included things like sleep, appetite, eyesight, hearing and smoking.
- Capitals, assets and resources included things like neighbourhood characteristics and social networks.
- Managing everyday life with dementia included things like dependence in daily activities.
- Social location included things like status in the local community.

For each domain, we identified which of the things in that category were most strongly linked to living well. While most aspects within each domain were linked with living well, some were more strongly related than others.

We took the aspects within each domain that were most strongly related to living well and combined those into a single score for that domain, ready for the next stages of the analysis.

First we investigated whether the domains were individually linked with living well. We found that all five domains were associated with ability to live well. People who made more positive ratings in each domain were likely to have better ‘living well’ scores.

Then we looked at all the domains together to see which were most strongly linked to living well. We found that psychological characteristics and psychological health was the domain most strongly linked to the ‘living well’ score. This suggests that people who have good psychological well-being are most likely to see themselves as ‘living well’ with dementia.

When put together with psychological characteristics and health, the other domains did not have an independent link with ‘living well’. Nonetheless, these other domains of life are still important for living well. Experience in the other four domains is likely to influence psychological well-being. For example, good physical health, feeling valued in one’s community, and being able to manage daily tasks independently are all things that could influence a person’s outlook on life.

Following on from this analysis we will look at each of the five domains in more detail to understand more about how these different aspects of life are linked with ‘living well’ for people with dementia.

The understanding we gain through these analyses will help in developing new or better ways of improving the ability to ‘live well’ with dementia.