Living well with dementia: early findings from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study

Linda Clare and Keith Oliver on behalf of the IDEAL team and ALWAYs group

www.exeter.ac.uk/psychology/reach
‘Living well’ with dementia

• Increasingly mentioned in policy documents relating to dementia
• No specific definition and no specific measures
• ‘Living well’ with chronic illness and disability has been defined as:
  ‘[experiencing] the best achievable state of health that encompasses all dimensions of physical, mental and social well-being’ and ‘a self-perceived level of comfort, function and contentment with life’ (Institute of Medicine, 2012)
• Key indicators would be quality of life, satisfaction with life and subjective well-being
• The IDEAL programme set out to investigate what it means to ‘live well’ with dementia and how we can optimise the potential for people with dementia and carers to ‘live well’
The IDEAL programme

- Longitudinal cohort study in Great Britain
- Initially recruited 1547 people living with mild-to-moderate dementia (MMSE >14) with 1283 carers
- Six yearly waves of interviews with questionnaires and open-ended questions – years 1-3 and 5-7; smaller group selected for qualitative interviews
- Linkage with administrative data on service use
- Additional workstreams focus on inclusion of ‘seldom heard’ groups and co-production of measures
- Arts-based project ‘A Life More Ordinary’
- Strong PPI emphasis with experts by experience advising the research team
The IDEAL cohort at Time 1: 1547 people living with dementia in Great Britain

**Gender**
56% male  
44% female

**Age**
Mean 76.37 yrs. (range 43-98)  
Age distribution  
<65 years: 9%  
65-69 years: 11%  
70-74 years: 17%  
75-79 years: 24%  
80+ years: 39%

**Education**
No qualifications 28%  
School Leaving Cert at age 16: 18%  
School Leaving Cert at age 18: 34%  
College 20%

**Marital Status**
74% married, civil partnership, cohabiting  
17% widowed  
6% divorced  
3% single, separated, other

**Living Situation**
80% live with others  
20% live alone

**CARERS (n=1283)**
31% male  
69% female  
80.9% spouse or partner  
19.1% other family member or friend
Dementia diagnoses in the IDEAL cohort

- Alzheimer's disease: 56%
- Vascular dementia: 11%
- Mixed: 21%
- Frontotemporal disease dementia: 4%
- Lewy body dementia: 3%
- Unspecified dementia: 3%
- Other: 2%
- <1%

Cognition scores:
- MMSE Scores: Median 23 (range 14-30; max. 30)
- ACE-III Scores: Median 70 (range 21-99; max. 100)
Key questions for this presentation

• What aspects of people’s experience are associated with the capability to ‘live well’ with dementia?
• Which aspects have the strongest links with living well?
What do we know already about factors linked with ‘living well’ for people with dementia?

• There have been many studies of quality of life, but fewer of satisfaction with life or well-being

• Numerous aspects of people’s experience are linked with quality of life – but each one only to a small degree

• Most likely these aspects are different for different people

Martyr et al., 2018, Psychol Med
What does living well mean to individual IDEAL participants? Some examples:

<table>
<thead>
<tr>
<th>Category</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships</td>
<td>We’re in it together</td>
</tr>
<tr>
<td></td>
<td>Having friends</td>
</tr>
<tr>
<td>Health</td>
<td>Health comes first</td>
</tr>
<tr>
<td>Staying positive</td>
<td>Being useful</td>
</tr>
<tr>
<td></td>
<td>Important to keep motivated</td>
</tr>
<tr>
<td></td>
<td>Not being despondent despite frustration</td>
</tr>
<tr>
<td>Looking after yourself</td>
<td>Staying safe in my house</td>
</tr>
<tr>
<td>Enjoying life</td>
<td>Getting out and about</td>
</tr>
<tr>
<td>Managing well</td>
<td>Manage every day to the best of my ability</td>
</tr>
<tr>
<td></td>
<td>Balancing what I want to do and what I can do</td>
</tr>
</tbody>
</table>
Measuring whether someone is ‘living well’ in IDEAL

- **Living well**
  - **Quality of life**
    - Aspects of your life e.g. health, mood, family, friends, life as a whole
    - 13 item QoL-AD scale
  - **Satisfaction with life**
    - Feelings of satisfaction with your own life
    - 5 item SwLS scale
  - **Well-being**
    - Positive mood, being active, and being interested in things
    - 5 item WHO-5 well-being index
Understanding influences on ‘living well’ in IDEAL

RESOURCES
Accumulated experiences, capitals, assets and resources:
  Social
  Environmental
  Psychological
  Economic
  Physical

CHALLENGES
Impact of disability resulting from development and progression of dementia:
  Social
  Environmental
  Psychological
  Economic
  Physical

PERCEIVED CAPABILITY TO LIVE WELL WITH DEMENTIA
Measuring resources and challenges in IDEAL

Self-ratings in five domains of life with multiple measures in each domain:

- Psychological characteristics and psychological health
- Physical fitness and health
- Capitals, assets and resources
- Social location
- Managing everyday life with dementia
Building a model of what contributes to ‘living well’

1. For each of the 5 domains, all the relevant variables were analysed to see which were linked with living well. We retained the variables that were statistically significant and had meaningful effect sizes for the next stage.

2. For each domain these variables were combined to give one factor score. We calculated how strongly this was associated with the living well score.

3. We then combined all 5 domain factor scores in one analysis to see which were most strongly linked to living well, adjusting for age, sex and dementia sub-type.
### Variables included in each domain

<table>
<thead>
<tr>
<th>Domain</th>
<th>Variables included, and direction of association with better [+] or poorer [-] scores on living well measures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Psychological characteristics and psychological health</strong></td>
<td>Greater optimism [+]. Higher self-esteem [+]. More positive attitude to own ageing [+]. Lower subjective age [+]. Higher neuroticism [-]. More loneliness [-]. More depressive symptoms [-]. — <em>selected from 14 variables initially assessed</em></td>
</tr>
<tr>
<td><strong>Physical fitness and physical health</strong></td>
<td>Poor sleep [-]. Poor eyesight [-]. Poor hearing [-]. Poor appetite [-]. Change in olfaction [-]. Smoking [-]. Poor subjective health [-]. — <em>selected from 12 variables</em></td>
</tr>
<tr>
<td><strong>Capitals, assets and resources</strong></td>
<td>Greater cultural capital [+]. Isolation [-]. Lower neighbourhood reciprocity and trust [-]. — <em>selected from 9 variables</em></td>
</tr>
<tr>
<td><strong>Managing everyday life with dementia</strong></td>
<td>Greater disability [-]. Greater dependence [-]. — <em>selected from 3 variables</em></td>
</tr>
<tr>
<td><strong>Social location</strong></td>
<td>More positive social comparison [+]. Higher ranking of own status in community [+]. — <em>selected from 4 variables</em></td>
</tr>
</tbody>
</table>
Individual associations between domains and living well

<table>
<thead>
<tr>
<th>Domain</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological characteristics and psychological health</td>
<td>4.86 (95% CI: 4.54, 5.18)</td>
</tr>
<tr>
<td>Social location</td>
<td>-4.66 (95% CI: -5.72, -3.60)</td>
</tr>
<tr>
<td>Physical fitness and physical health</td>
<td>4.21 (95% CI: 3.84, 4.58)</td>
</tr>
<tr>
<td>Capitals, assets and resources</td>
<td>2.83 (95% CI: 2.23, 3.44)</td>
</tr>
<tr>
<td>Managing everyday life with dementia</td>
<td>1.98 (95% CI: 1.61, 2.35)</td>
</tr>
</tbody>
</table>
Full model including all domains together

Psychological characteristics and psychological health

Physical fitness and physical health

Capitals, assets and resources

Managing everyday life with dementia

Social location

Living well

QoL-AD

SwLS

WHO-5
Interpretation

• All domains have some relevance for ‘living well’
• The psychological domain is dominant when modelled together
• This may be partly because the constructs being rated are most similar to those included under ‘living well’
• However, experiences in other domains can underpin psychological health
• Psychological characteristics and health are likely to mediate the relationships between various domains of life and the extent to which people are able to ‘live well’
What does ‘living well’ with dementia mean at a personal level?

• Keith’s experience and perspective
What can we do to support ‘living well’?

• There is potential across many aspects of life to enhance resources and address challenges
• The biggest improvements may come from improving psychological health e.g. tackling depression and loneliness
• Enhancing capitals, assets and resources can support better psychological health e.g. increasing social engagement, reducing isolation, enhancing trust and support
• Enabling people to stay as physically fit as possible, and tackling other physical or health problems, is also vital
Practical action to support living well: ‘A Life More Ordinary’
Asserting the right to a ‘grand day out’
Raising awareness: the grand unfurling
Experts by Experience supporting IDEAL

ALWAYs (Action on Living Well: Asking You)

Our advisory group of people with dementia and carers, the ALWAYS group, advises on aspects of the project, based on personal experience, skills and expertise. For example, the members have:

- Advised on how to explain aspects of the study when seeking consent
- Piloted the qualitative interviews
- Helped to interpret the findings and link these to people’s lived experience
- Advised on making a new questionnaire accessible
- Participated in the formal project advisory group
- Presented findings at conferences and events
The ‘Improving the Experience of Dementia and Enhancing Active Life’ (IDEAL) programme collaborated with people living with dementia, carers and researchers...
The ALWAYSs group experience

• Keith’s perspective
Moving things forward
IDEAL Programme: Acknowledgements

IDEAL co-ordinating centre
Prof Linda Clare (CI)
Dr Sharon Nelis
Dr Catherine Quinn
Dr Anthony Martyr
Dr Ruth Lamont
Dr Marta Bienkiewicz
Dr Jemma Regan
Dr Rosalie Ashworth

Project staff
Dr Alex Hillman
Dr Cate Henderson
Dr Isla Rippon
Dr Yu-Tzu Wu
Nicola Hart
Bryony Longdon
Annette Wolske

Collaborators
Dr John Hindle
Rachael Litherland
Prof Fiona Mathews
Prof Robin Morris
Dr James Pickett
Prof Jennifer Rusted
Dr Jeanette Thom
Prof Christina Victor
Prof Ian Rees Jones
Prof Roy Jones
Prof Martin Knapp
Prof Michael Kopelman
Prof Clive Ballard
Prof Julian Hughes

Research networks
Clinical Research Network researchers who collect data for the study.
NWORTH and Exeter Clinical Trials Units.
Dr Helen Collins

IDEAL people
We would like to thank all of our participants for contributing to the study

Members of the
ALWAYS group
Project Advisory Group - chaired by Dr Nori Graham

A Life More Ordinary artists:
Ian Beesley
Tony Husband
Ian McMillan

Funding
The IDEAL study is funded by the Economic and Social Research Council (UK) and the National Institute for Health Research (UK) through grant ES/L001853/2 ‘Improving the experience of dementia and enhancing active life: living well with dementia’
Funding from the Alzheimer’s Society, UK grant number 348 (AS-PR2-16-001) will cover continued follow up from 2018-2022.

www.idealproject.org.uk  @IDEALStudyTweet