A Person-Centred Approach to Dementia: A Policy Proposal for Improving Dementia Care in the U.K.

Leo Kremer, Deepa Selvaraj, Toby Shevlane, and Jeff Sload

University of Oxford
Department of Social Policy and Intervention
Social Policy Analysis
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### Proposal Overview

<table>
<thead>
<tr>
<th>The Social Problem</th>
<th>Current Landscape</th>
<th>Theoretical Perspectives</th>
<th>Policy Proposal</th>
<th>Barriers and Implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Background</strong> on dementia as a disease and social issue</td>
<td>Care is provided through a division of labor between formal and informal caregiving</td>
<td>Different approaches demand different policy solutions. A holistic approach provides the theoretical underpinning to our policy solution.</td>
<td>In residential care homes, staff will be trained to adopt a person-centred approach. <strong>Neighbourhoods</strong> will be renovated to make them dementia-friendly.</td>
<td>Our proposal demands initial increases in residential care costs and in funding neighborhood renovation. There may be political resistance.</td>
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<td><strong>Demographic shift and fiscal pressures</strong> make dementia care a critical challenge of the 21st century</td>
<td>Cost is split between public and private sources</td>
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The Social Problem: Demographic shift and fiscal pressures make dementia care a critical challenge of the 21st century.
Dementia is a cognitive disorder resulting from a number of diseases

- Group of related symptoms indicative of decline in brain functioning (NHS Choices, 2017)
  - Memory loss
  - Language impairments
  - Judgement problems
  - Mood problems
  - Movement problems
  - Difficulties carrying out daily activities

- Some subtypes:
  - Alzheimer’s disease (62%)
  - Vascular dementia (17%)
  - Mixed dementia (10%)

- Leading cause of death for females, 2nd leading cause for males (ONS, 2017)
The prevalence of dementia increases sharply with age.
Population aging will cause a doubling of the U.K. dementia population by 2050

- Demographic ageing
- Estimated increase in dementia sufferers: 32% by 2025, 147% by 2051

Source: Alzheimer's Society, 2014
The increasing dementia population will lead to an increasing financial burden

- According to the Alzheimer’s Society (2014), currently £26.3 billion a year
  - More than costs of cancer, heart disease, or stroke
  - ‘Enough to pay the energy bills of every household in the country’
- Costs expected to be tripled by 2040
Dementia patients currently have poor quality of life

- A large UK study revealed that 20.5% of dementia patients had depression, compared to 8.6% of those without dementia (Winblad et al. 2004)
- Results of recent inspections on 725 care homes: around 44% rated as ‘inadequate’ or ‘requiring improvement’ overall (Care Quality Commission, 2017)
- 1 in 4 ratings of care homes on the Good Care Guide are ‘poor’ or ‘bad’ (Knapton, 2017)
  - For instance, there were complaints of inadequately trained staff who did not know how to lift patients or care for people with dementia
- Although they value being able to walk outside, they get anxious and disoriented in complex, busy or loud places (Mitchell & Burton, 2010)
The U.K. government recognises the issues posed by dementia and is attempting to address them

"the new Challenge aims to make England, by 2020, the best country in the world for dementia care, support, research and awareness"
Care Landscape: A division of labor between formal and informal caregiving
Policy is formulated and implemented via various structures

- Devolution:
  - England, Scotland, Wales and Northern Ireland all have separate powers to introduce policies concerning dementia
- Policy implementation overseen by Department of Health
  - NHS: GPs, nurses, specialists, medical staff
  - Local authorities: social services department
  - Private businesses: residential care homes
Healthcare is administered by the NHS and social care is taken care of by local authorities.

- **GP appointment**
  - Diagnosis
  - Assessment of future health and social care needs
  - Creation of a health care plan

- **Healthcare (NHS)**
  - Treatment from GP and hospital
  - Community mental health nurses
  - Specialist services: physiotherapy, speech and language therapy, mobility specialists etc
  - Nursing care received in nursing home*

- **Social and personal care (Local authorities)**
  - Local social services department
  - Assessment of care and support needs
  - Provide advice and support options
There are five key types of social care available to people with dementia.

<table>
<thead>
<tr>
<th>Homecare</th>
<th>Community support or activities</th>
<th>Unpaid care</th>
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</table>
| • Long-term, 24-hour care  
  • Day care  
  • Short breaks for unpaid carer  
  • Emergency care | • Local authorities provide information on what services are available | • Family or friend as caregiver |
| Day centres       | Residential care homes                                                |                                    |
| • Provides meals, opportunities to socialise and other activities | • With or without nursing care |                                    |
Dementia is a complex problem with many potential areas for intervention.

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**NHS, local authorities**

**Undiagnosed Dementia Population**
- Expected to grow substantially with population aging
- Diagnosis (current rate 67%)

**Diagnosed Dementia Population**
- Expected to grow substantially, even faster than undiagnosed

**Treated Dementia Population**
- Care delivery

**Exit to Acute Care, Death**

**Funding, regulation, training, oversight**

**Care Landscape**
- Disease prevention, improving health outcomes
- Nursing homes, home care, etc.
Theoretical Perspectives: Different Approaches to Dementia
Multiple theoretical ‘starting points’

Due to the multidisciplinary nature and multiprofessional nature of dementia, the discourse around dementia care practice is such that the underlying assumptions of recommendations are blurred or implicit.

It is vital to not only understand how particular perspectives shape policy, practice, and research directives...

...But also to be aware of the multiple theories that shape dementia discourse.

‘Confused professionals’

Aim: To ‘untangle’ the different theoretical models, perspectives, and approaches often used when discussing dementia.
The biomedical perspective: emphasizing the disease process

- For over a hundred years there has been interest in dementia from biomedical disciplines and health professions, where the key concern was around understanding the disease process.
- The biomedical model has three main propositions:
  - Dementia is a pathological, abnormal condition.
  - Dementia is organic in aetiology and progresses through stages.
  - Dementia is diagnosed using biomedical assessments.
## Biomedical Perspectives: Benefits and Limitations

### Biomedical Perspectives: evaluation

<table>
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<tr>
<th>Benefits</th>
<th>Limitations</th>
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| ● Provides a *way to cope* with the challenges of caring for a dementia patient.  
● Provides a *differential diagnosis*.  
● *Reduces the stigma* often associated with conditions seen as mental health conditions. | ● What is missing: the *views and experiences* of the person with dementia.  
● ‘Cause: *unknown*; diagnosis: *very difficult until after death*’ (Harding and Palfrey, 1997, p.34) |
A person-centred care approach provides practitioners with a framework of values that are ethical, humanitarian, and respectful of the person with dementia.

The introduction of personhood: ‘a status or standing bestowed upon one human being, by others, in the context of the social relationship and social being. It implies recognition, respect, and trust.’ (Kitwood, 1997, p.8)

- A focus on the self and awareness.
- A person-centred care approach provides practitioners with a framework of values that are ethical, humanitarian, and respectful of the person with dementia.
## Psycho-social Perspectives: evaluation

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<th>Benefits</th>
<th>Limitations</th>
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<tr>
<td>● Reminds carers and professionals of the importance of <strong>focusing on the individual</strong> person with dementia.</td>
<td>● <strong>Outcome measures</strong> for person-centred care remain elusive;</td>
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<tr>
<td>● <strong>Highlights possible therapies and interventions</strong> that might be useful for the individual, or for their family to help support.</td>
<td>● As does <strong>widespread change</strong> in care practices.</td>
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<td></td>
<td>● <strong>A failure to locate analysis</strong> of experiences of individuals within wider social, political, cultural and economic concerns.</td>
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The wider social and structural factors that shape an individual’s experience of dementia must be utilized.

A consideration of life with dementia that can remain fulfilling: there is ‘life beyond the illness’.

Goes beyond the individualism promoted by social psychology;

Goes beyond the disease labelling of biomedical perspectives.

Our policy solution: straddling the intersection.
Taking a Holistic Approach to Dementia Care and Treatment

Dementia is a condition that can be understood from biomedical, psychosocial and gerontological vantage points.

Dementia research will focus on macro and micro level issues to promote a broader understanding of the worlds of professionals, carers and people with dementia. This would be contextualised within policy frameworks and societal expectations and beliefs about dementia and quality care.

Policy frameworks need to reflect biomedical knowledge and psychosocial concerns about the individual, while recognising the disadvantage(s) older people face in society.

Care practices need to take account of individuals and their neurological impairment, while taking account of the structural constraints in providing high quality care.

Figure 1.1: A web of understanding dementia using an integrated perspective

Innes, 2014, p.36
Proposed Policy: Person-Centred Approach to Neighborhoods and Residential Care
Person-Centred Care is an integrative approach to improve Quality of Life

What is person-centred care? (PCC)

- Kitwood: person-centred care (PCC) as distinguishable from medical care, importance of contact and communication (Kitwood, 1997)
- In dementia, patients have selfhood, rights, and need for sensitive interaction

PCC in the U.K.

- PCC for elderly is Standard 2 of the National Service Framework, with reporting towards this standard required (Brooker, 2003)
- Nonetheless, person-centred care remains an ambiguous term, and although widely advocated, specific practices have not been implemented (Edvardsson, 2008)
Person-Centred Care remains an ambiguous term, with recent efforts seeking to refine measurement tools (1/2)

“Person-centred care is a philosophy that sees patients as equal partners in planning, developing and assessing care to make sure it is most appropriate for their needs. This involves patients and their families being at the heart of all decisions. Services are reorientated to be user-focused, to promote control, independence and autonomy for the patient and the carers and family, to provide choice and be based on a collaborative team philosophy.”

- Debra De Silva, The Evidence Center, in a systematic review of PCC (Da Silva, 2014)
Person-Centred Care remains an ambiguous term, with recent efforts seeking to refine measurement tools (2/2)

Measuring PCC (Da Silva, 2014)

- No universally agreed-upon measurement criteria (holistic vs specific)
- Techniques include **surveys** of clinicians and patients as well as **direct observation** of caregiving by evaluators
PCC shows improved care quality in residential homes, and reduced burden on health services, broadly

Experimental outcomes from PCC training in residential care homes:

○ Reduced **agitation** and **aggression** (Sloane, 2004; Chenowith, 2009)
○ Reduced administration of **antipsychotic medication** (Fossey, 2006)
○ More **gentleness** and greater perception of **ease** in caregivers (Hoeffler, 2006)

Systematic reviews of PCC & related practices find:

○ Increased self-management of care reduces **health service visits**, **improves clinical outcomes**, **quality of life**, and **care behaviors** (Da Silva, 2011)
○ Shared decision-making improves **patient satisfaction**, and may improve clinical outcomes and resource use (Da Silva, 2012)
Policy: Transitioning to PCC in UK Residential Care Facilities

- In 2013, there were 12,848 registered residential care homes (with 244,232 beds) for adults and older people in England, as well as 4,664 nursing homes (with 218,678 beds) (NICE, 2015)
- We propose **annual training, observation, and surveying** of PCC in 1000 residential care facilities across the UK
- We would also intend to make additional money available, through research grants, for researchers looking to improve the implementation and measurement of PCC
PCC in U.K. Residential Care Homes will Improve Care Quality

Based on the literature previously referenced, the following are the intended outcomes of increasing PCC training and research:

- Reduced **agitation** and **aggression** of dementia residents
- Reduced **antipsychotic drug use**
- Reduced medical care **costs** per dementia resident (more theoretical)
- Improved **outlook** of caregivers
- Improved **measurement and implementation** of PCC
Neighbourhood

- Existing approaches to person-centred care “fail to locate the person with dementia as an active participant in their community/neighbourhood”.
  
  (Keady et al 2012)

- A respect for personhood is incompatible with social isolation.

- Less than half (47%) of dementia sufferers feel a part of the community.

  (Alzheimer’s Society Survey, 2013)
Findings from the review: social capital

- Social capital, as applied to older people:
  
  “the array of social contacts that give access to social, emotional and practical support”

(Gray 2009)
“Regular interaction with the same people in the same places builds familiarity and a broader sense of belonging.”

(Ward et al 2017)

Store keepers, hairdressers, joggers improving sense of belonging.

- Psychologists have developed “self determination theory” (see Ryan and Deci 2002)
  - Mental wellbeing is improved by a sense of: autonomy, competence, belonging.
Findings from the review: walking

Walking around the community helps to...

- maintain cognitive functioning in those with dementia
- maintain the sense of self and well-being of a person with dementia
Findings from the review: walking

Higher rates of walking prompted by:

1. Feelings of safety
2. Trust of neighbours
3. Access to greenery

And “negative aspects of the built environment that are traditionally associated with disadvantaged areas” correlate with “reduced walking and lower levels of mental well-being”.
Findings from the review: walking and shopping

New technology causes problems (Brorsson et al 2011)
Walking clubs

R. lit up when we walked by the dog park today...

She spent the next 15 minutes or so handing out dog cookies, patting the odd dog, clearly loving it.

Later...she said “They ... you know ...” She paused. “…respond to me.”

(Phinney et al 2016)
Council-led intervention

Empower local authorities through a **dementia community fund**.

To be spent on targeted:

1. Signage
2. Walking groups
3. Greenery
4. Dementia-proofing of shops
5. Recruitment of dementia friends
Barriers and Implementation: Cost and Politics
Implementation will require funding from the NHS or Dementia/Alzheimer’s groups.

- Total estimated cost for PCC training and observation, appx. **£3 million annually**
- The NHS and NICE regularly engage in similar types of surveys to those proposed, so including questions on PCC would represent **little incremental cost** (Da Silva, 2014).
- Costs associated with dementia-friendly neighborhoods are likely to be **highly variable and difficult to calculate**, but represent a large **up-front cost**
- Better Care Fund, **£5.9 billion pounds**

### PCC Costs

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<td>Residential Training</td>
<td>£1.5 million per year</td>
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<td>1000 facilities * £1400 = ~ £1.5million (Chenowith, 2009)</td>
</tr>
<tr>
<td>Observation</td>
<td>£1.5 million per year</td>
</tr>
<tr>
<td></td>
<td>Assume similar costs for similar staff as residential training</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>~£3 million per annum</td>
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There are political barriers...

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<th>Residential Care PCC</th>
<th>Dementia-Friendly Neighborhoods</th>
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<tr>
<td>● Difficulty of expanding health care costs in climate of <strong>austerity</strong></td>
<td>● 59% of UK adults surveyed in the YouGov poll feel that the inclusion of people with dementia in the community is <strong>fairly bad or very bad</strong></td>
</tr>
<tr>
<td>● Strong <strong>regulation</strong> of private/public facilities reverses trend of increasingly privatized provision of health care in the U.K.</td>
<td>● Initial <strong>implementation costs</strong></td>
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<td>● Difficulty in making structural changes to <strong>privately owned land</strong></td>
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...but also strong interest groups and a central position on the current political agenda

Interest Groups

- Alzheimer's Society is well-funded and influential

Political Agenda

- London pushing to become dementia friendly
- 1.4 million people becoming Dementia Friends and 142 communities to date across England signed up to be Dementia Friendly Communities
- Prime Minister’s Challenge on Dementia 2020: clear goal to ensure best care is provided to every person with dementia, with focus on staff training.
There are possible gaps and pitfalls in implementation

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<th>Implementation Challenges</th>
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<td><strong>Residential Care PCC</strong></td>
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<td>● Caregiver buy-in (previous studies have shown little difficulty with this, however)</td>
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<td>● Logistical challenge of oversight across so many facilities</td>
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<tr>
<td><strong>Dementia-Friendly Neighborhoods</strong></td>
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<tr>
<td>● Local authorities and contractors may not have a clear idea of what is needed, in terms of the structural changes (e.g. dementia-friendly signage)</td>
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Conclusion
Dementia is a major challenge for the 21st century due to population aging, rising medical costs, and increased diagnosis.

Person-Centred Care (PCC) focuses on treating dementia patients as autonomous individuals who (along with their families) can and should be involved in the caregiving process.

Improving PCC through residential care staff training and through better equipping neighborhoods to handle dementia patients has the potential to improve health outcomes, quality of life, and cost.

There is likely to be a substantial fiscal barrier to incomplete implementation of this proposal, and there may be an attitude barrier towards dementia-friendly neighborhoods.
Thank you for considering our proposal
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Alzheimer’s Society (2014). Dementia UK Update.


Brorsson, Anna ; Öhman, Annika ; Lundberg, Stefan ; Nygård, Louise. Being a pedestrian with dementia: A qualitative study using photo documentation and focus group interviews. Dementia, 2016, Vol.15(5), pp.1124-1140


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