Long Term Residential Care for people with dementia in Ireland. New findings from a DSIDC National Survey

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Dementia- a key predictor of need for long term residential care and many people with severe dementia require residential care (Butcher et al., Caron, Ducharme & Griffith, 2006; Castle, 2001; Park, Butcher & Maas, 2004; Thorson & Davis, 2000). 2001; Ryan & Scullion, 2000).

Challenging behaviours, the absence of adequate community supports and caregiver burden are all key factors contributing to the breakdown of community care (Naleppa, 1997; Pinquart & Soerensen, 2003; Smith & Crome, 2000).

On average people with dementia in residential care are older and have more severe dementia than community dwellers (Meehan et al., 2004; Schulz et al., 2004;)

The average length of stay for people with dementia in residential care is longer (Australian and New Zealand Society for Geriatric Medicine, 2011).
The International Context


- These facilities are called different names, but each is underpinned by similar person centred principles which promote autonomy, choice, participation and empower the individual (Verbeek, 2011).

- Dementia specific long term care:
  - US, 17%
  - Norway and Sweden about 20%
  - Luxembourg 40%
  - The Netherlands 25%, with a commitment to increase to 33% by 2015 (De Lange et al., 2011).
Best Practice in Dementia Care

- Separate rooms for separate functions
- Individual en suite bed rooms
- Small scale domestic units (< 10 residents)
- Staff are dementia trained
- Meaningful activities (domestic and therapeutic)
- Therapeutic gardens
- Unobtrusive concern for safety
- Control of noise and external stimuli (Judd, Marshall, Phippen, 1998)
The Irish Context

- No database/register of dementia specific units.
- No information of how many SCUs exist & where they are located.
- No data on who the main providers are: private, private and voluntary.
- Lack of knowledge about the ethos and approach to care and the extent to which facilities operate comply with best practice.
- A need to address this gap in our knowledge and understanding and to develop a directory of SCUs.
Key Research Questions

- Who are the main providers of long term residential care to older people in the Republic of Ireland?

- Who are the main providers (private, public and voluntary) of long term specialist dementia care?

- How many, and where are these SCUs located in Ireland?

- To what extent do SCUs comply with best practice principles?
Research Methods

- Population of complete coverage - all long stay residential care facilities for older people in Ireland (N=602)
- Self administered questionnaire designed and pre-tested.
- Two part questionnaire, Part A for all Nursing Homes and Part B for Specialist Care Units only.
- Data collected by this self administered questionnaire and later by telephone interviews.
- Response rate was 78%.
## Table 1: Response rate

<table>
<thead>
<tr>
<th>Method</th>
<th>Date</th>
<th>Returned/Completed Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self administered questionnaire circulated to 603</td>
<td>September and October 2013</td>
<td>302</td>
</tr>
<tr>
<td>Email contact made with questionnaire attached</td>
<td>November 2013</td>
<td>44</td>
</tr>
<tr>
<td>Telephone contact and telephone interview Two additional returns</td>
<td>January 2014</td>
<td>121</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>469</strong></td>
</tr>
</tbody>
</table>
Figure 1: Nursing Home Population by Provider Type

- Private: 65%
- HSE: 22%
- Voluntary: 13%
Number of SCUs
Figure 2: Number of SCUs by Provider Type

- Analysis based on 54 self identified SCUs providing care to 1034 PwD (2% of population of PwD in Ireland or 4.5% of all people in long stay care).

- Only 5% of all residents in these SCUs aged less than 65 and only 1 person had AD related to Downs’ Syndrome.

- 66 respite beds were available across 54 SCUs – most of which (over two thirds) were provided by the HSE.
Location of SCUs in Ireland (N=54)
Table 2: Examples of Inequalities in Service Provision across the Republic of Ireland

<table>
<thead>
<tr>
<th>LHO Area</th>
<th>No. of SCUs</th>
<th>LHO Area</th>
<th>No. of SCUs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cork</td>
<td>13</td>
<td>Dublin North East</td>
<td>0</td>
</tr>
<tr>
<td>Cavan/Monaghan</td>
<td>5</td>
<td>Dublin West</td>
<td>0</td>
</tr>
<tr>
<td>Donegal</td>
<td>5</td>
<td>Dublin North Central</td>
<td>0</td>
</tr>
<tr>
<td>Galway</td>
<td>5</td>
<td>Dublin North West</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Carlow</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wicklow</td>
<td>0</td>
</tr>
</tbody>
</table>
Other Key Findings

- Size of Units
- Physical Layout
- Admission Policy
- Activities
- Staff Training
- End of Life Policy
Size of Units
Figure 3: Size of SCUs based on Number of Residents

- 10 or less residents: 9
- 11-15 residents: 16
- 16-20 residents: 7
- 21-30 residents: 13
- 31-40 residents: 4
- 40-60 residents: 5

Average number of residents: 19.1
The Physical Environment of Specialist Care Units
Figure 4: The Provision of Single Bedrooms by Provider Type (N=54)

- **Private**: 23 residents have their own bedroom, 11 do not.
- **HSE**: 2 residents have their own bedroom, 14 do not.
- **Voluntary**: 4 residents have their own bedroom, 0 do not.

- All residents have their own bedroom
- Not all residents have their own bedroom
Admission Criteria used
Figure 6: Provider type and Admission Criteria used (N=54)

- Pre Admission Assessment
  - Private: 32
  - HSE: 12
  - Voluntary: 4

- Clinical Diagnosis
  - Private: 19
  - HSE: 13
  - Voluntary: 4

- Behaviours that Challenge
  - Private: 13
  - HSE: 8
  - Voluntary: 1

- Be independently mobile
  - Private: 11
  - HSE: 6
  - Voluntary: 2

Legend:
- Private
- HSE
- Voluntary
Therapeutic Gardens and Meaningful Activities
Therapeutic activities and Multi Sensory Gardens

- Wide range of activities noted including aromatherapy, music & art therapy, Sonas program and yoga.
- Almost all (89%) of SCUs had a therapeutic garden.
- Some examples of creativity and best practice:
  - “Some residents are retired mechanics and teachers. We have placed a car in the courtyard to facilitate this and developed a teachers corner with blackboard and visits to schools for those retired teachers”

Garden design from Nightengale House Care Home London
Figure 7: Domestic Activities offered by SCUs by provider type (N=54)

- **Private**
  - Gardening: 26
  - Cooking Light Meals: 17
  - Own Laundry: 10
  - None: 5

- **HSE**
  - Gardening: 11
  - Cooking Light Meals: 5
  - Own Laundry: 5
  - None: 5

- **Voluntary**
  - Gardening: 4
  - Cooking Light Meals: 2
  - Own Laundry: 1
  - None: 0
Dementia Specific Training
Staff Training

- Nursing Staff
- Health Care Assistants
- Other Staff
Figure 8: Dementia Specific Training: Nurses and HCAs (N=54)

- **Nurses Private**
  - No response: 15
  - None: 19

- **HCAs Private**
  - None: 14
  - All: 20

- **Nurses HSE**
  - None: 10
  - Some: 6

- **HCAs HSE**
  - None: 12
  - Some: 8
  - All: 5

- **Nurses Voluntary**
  - None: 2
  - All: 2

- **HCAs Voluntary**
  - None: 2
  - All: 2
Figure 9: Dementia Specific Training: Other Staff (N=54)
End of Life Care Policy
End of Life Care Policy

- Majority (89%) provided rich and detailed written narratives on EOL

- Four key themes emerged:
  - Involvement of family members
  - Palliative Care
  - Dignity and Respect
  - Transfer
Typical Responses

“All residents should have the right to privacy and dignity at end of life. Their wishes and beliefs are recorded in their care plan. If the residents is unable to voice this, the information is obtained from the family or next of kin and from the resident’s life history”

“An individualised person-centred care plan is documented for all residents with dementia. Decisions regarding end of life care are collaborative and made in the best interest of the family”
Transferring out of SCUs at End of Life

- Seven SCUs (14%) reported a policy of either always or sometimes discharging residents with dementia from SCUs at end of life. This practice of discharging residents at end of life was more common in HSE SCUs.

- “Following assessment and consultation with the next of kin, transfer to a long stay unit (occurs) where end of life care can be given with access to the home care team if required”

- “As residents move to a stage of dependency we maintain that as it is a dementia unit, that they are prepared (family members) for the move to another unit in our facility..”
Discussion

- The survey identified 602 long stay residential care settings across the ROI, most of which were operated by private providers (65%).

- The survey also found 54 self identified SCUs who provide specialist long term residential care to some 1034 men and women with dementia.

- Within each SCU, results showed that numbers of residents varied, but most SCUS are larger than what is recommended by best practice guidelines and by Irish Supplementary Standards for SCUs (HIQA, 2009,19: 10)
Discussion

- The survey found that private operators are the dominant providers even though no supplementary bed-rate is paid, and there is no financial incentive to encourage necessary capital investment.

- Location of SCUs appears arbitrary and coherence in provision will be dependent on policy reform.

- Some unexpected findings in relation to admission policies, respite care provision and EOL practice in some HSE units.

- Despite the expected increase in prevalence of dementia in Ireland, no significant expansion in supply is likely in the foreseeable future.
Conclusions

- Expanding the supply of dementia specific beds in SCUs may be dependent on the NTPF rates being more realistically linked to dependency levels of residents.

- Results also have implications for best practice and for HIQA particularly in light of its current review of residential care standards.

- These findings have been used to compile a guide on SCUs for family caregivers and health service professionals.
Acknowledgements

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References

- Australian and New Zealand Society for Geriatric Medicine (2011) Position Statement No’s 9 and 10 The Geriatricians’ Perspective on Medical Services to Residential Aged Care Facilities (RCFs) in Australia. (Revised August 2011 )
References


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