

Long Term Care and People with Dementia in Ireland: A Case of surviving or thriving in Irish Nursing Homes?

Suzanne Cahill, PhD, Associate Professor
The Dementia Services Information and Development Centre,

HIQA Seminar, Durkan Theatre, Trinity Health Sciences, St James's Hospital
November 4th 2013



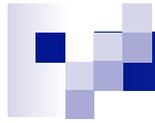
Acknowledgements



School
of Social Work
and Social Policy



The
ATLANTIC
Philanthropies



Outline

New Dementia prevalence rates in Ireland

Estimates of Future Prevalence

Development of National Quality Standards

Quality of Life Issues

Future Directions

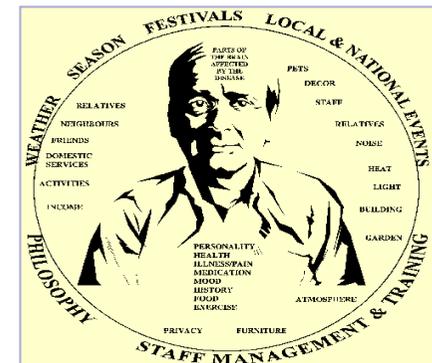
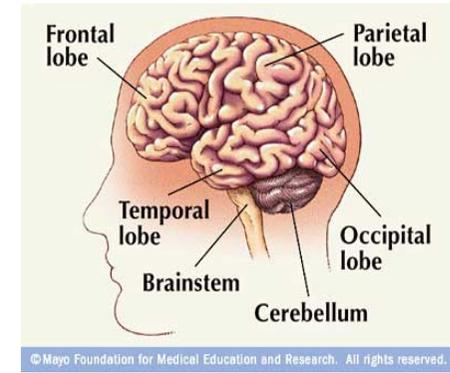


Current Realities

- Widespread fears, stigma and misconceptions about dementia held by both the public and professionals
- The paradox of dementia in long stay care: its invisibility yet dementia is probably the core business
- Major changes in the Long Term Care landscape since 2009 yet continued absence of knowledge and information about dementia
- National Residential Care Standards are being reviewed, but some major unresolved issues
- On the brink of developing a National Strategy on Dementia – what recommendations will be made for long term care?

What is dementia?

- Normal part of ageing
- Brain disease
- Mental health problem
- Disability



People with dementia and their family members: Some key figures

- Worldwide 35.6 million people living with dementia
- Expected to double every 20 years to 65.7 million by 2030 and to 115.4 million by 2050 (Prince, 2009)
- 47,746 people living with dementia in Ireland
- 50,000 family caregivers of people with dementia in Ireland (O'Shea, 2001)
- It has been said that for every one person diagnosed with dementia, three family members are significantly affected (Cahill et al., 2012).



Dementia Policy

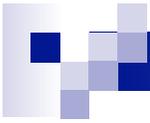
- Common policy initiative - to delay residential care
- When residential care is needed, range of options should be offered
- Care should be provided in small-scale homelike settings
- Respect for residents' autonomy and choice
- Recognition that challenging behaviours may be an expression of needs
- Normalization of daily life with person-centered care as central
- International consensus regarding the features and principles of good design for dementia (Judd, Marshall, & Phippin 1999)



Estimates of number of people with dementia in Ireland, 2011

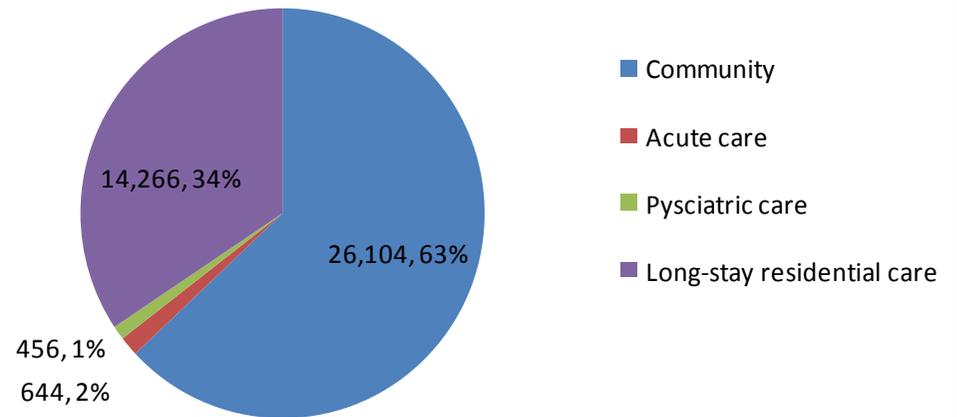
Age groups	Total Population (Census 2011)		Persons with dementia (estimated using EuroCoDe (2009) age/gender-related dementia prevalence rates)		
	Men	Women	Men	Women	Total
30-59 years	953,715	959,396	1907 ¹	959 ¹	2,866
60-64 years	109,869	108,917	220	980	1,200
65-69 years	86,298	87,340	1,553	1,223	2,776
70-74 years	63,476	67,714	2,031	2,573	4,604
75-79 years	46,631	55,405	3,264	4,211	7,475
80-84 years	28,423	41,690	4,121	6,837	10,958
85 years and over	18,486	39,930	4,289 ²	13,576 ²	17,867
Total	1,306,898	1,360,392	17,385	30,359	47,746

Source: Pierce, Cahill and O'Shea (forthcoming)



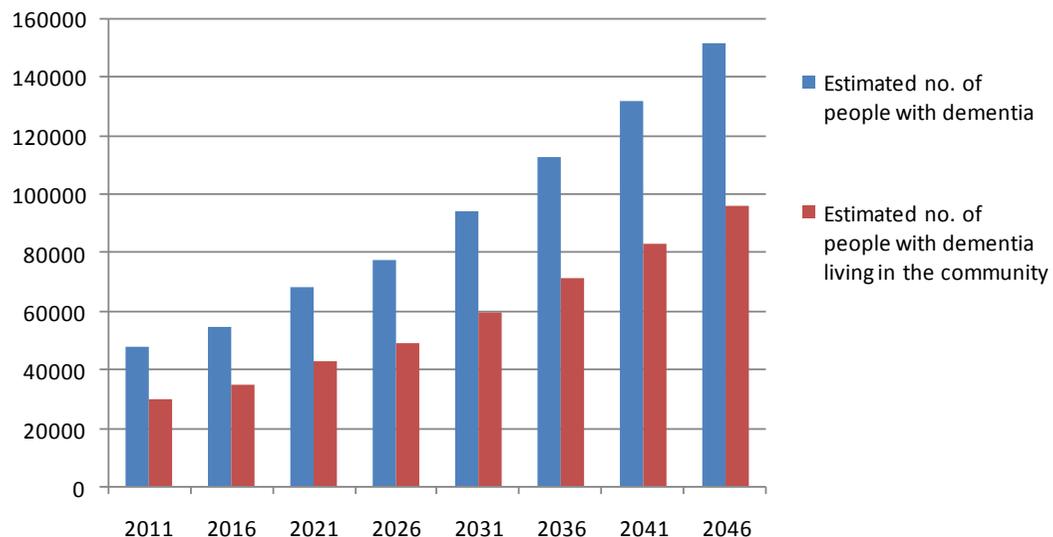
The majority of people with dementia (approx. 30,000) live in the community

Figure 1: Distribution of people with dementia across different care settings in Ireland



Source: Connolly et al., 2012.

Estimated and projected number of people with dementia in Ireland and living in the community, 2011-2046



Pierce and Cahill, forthcoming.

The number of people with dementia living in the community is expected to double over the next 20 years

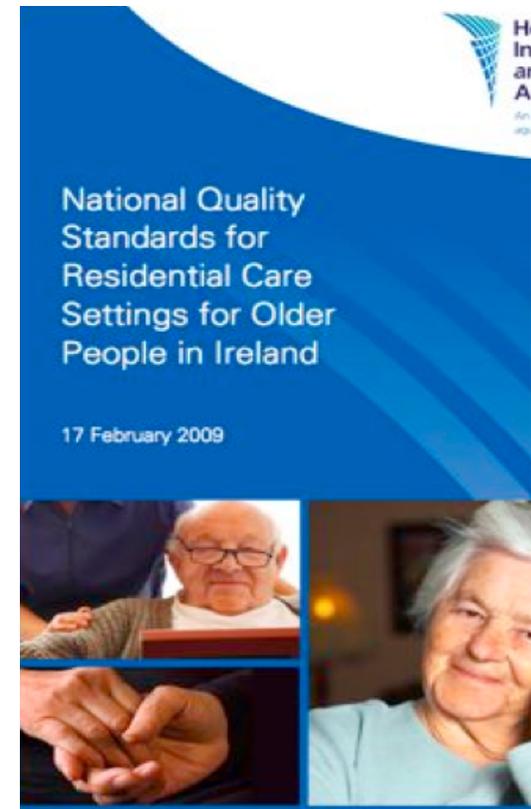
Before National Residential Care Standards

- Dominance of the Medical and Nursing model of care
- 1990: Nursing Home Act
- 1995: Nursing Homes Code of Practice.
- Calls for Accreditation and Standards
- 2006: Evidence of institutional abuse (Leas Cross- 2006)



Standards

- Rights
- Protection
- Health and Social Care
- Quality of Life
- The Environment
- Staffing
- Governance





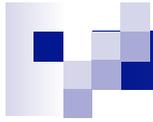
Negative and Positive outcomes of living in long stay care care

- Lack of privacy
- Lack of dignity
- Regimented routines
- Feeling of emptiness
- Improved self-worth
- Better morale
- Increased physical functioning

Who should define quality?

- Researchers?
- Practitioners?
- Inspectors?
- Family members?
- Residents?



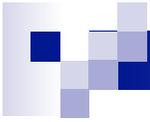


- What is life like for People with Dementia currently living in Irish Nursing Homes and how can quality of life be promoted?

?

Home Like?





Meaningful Activities?



Poly-Pharmacy and the over-prescription of drugs to PwD



Irish research



The under-detection of cognitive impairment in nursing homes in the Dublin area.
The need for ongoing cognitive assessment

(Cahill, Diaz-Ponce, Coen & Walsh, 2010)



Can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment?

(Cahill & Diaz-Ponce , 2011)



Dementia Prevalence is very high in nursing homes and like in the UK it has become the core business of long term in Ireland

Figure 4: Rates of Dementia and CI amongst NH using the MMSE (N=100)

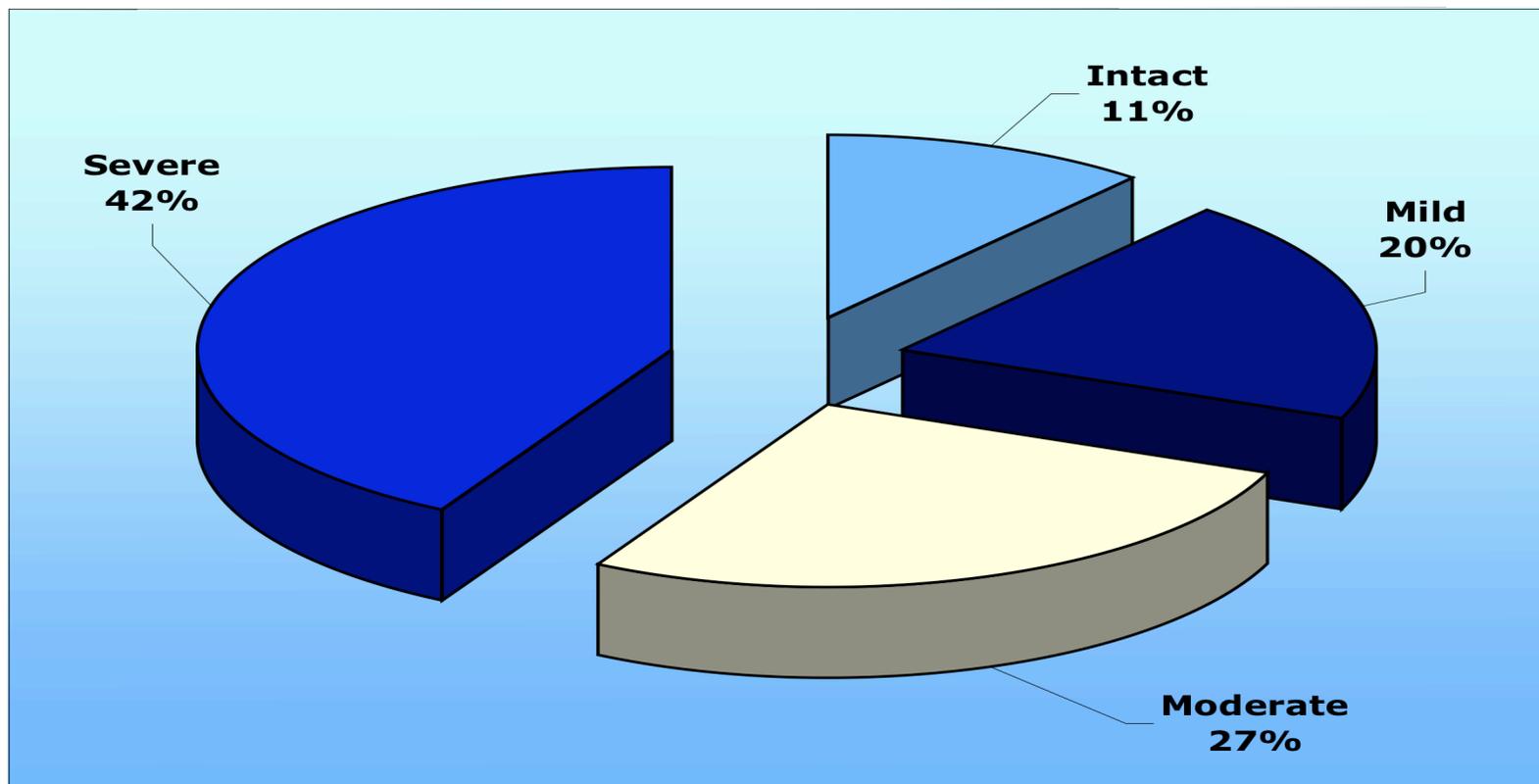


Table 3: Differences between Directors of Nursing perceptions of residents cognitive impairment & MMSE findings (N=100)

	Intact Matrons	Mild Matrons	Moderate Matrons	Severe Matrons	
Intact MMSE	34.80% 8	13.60% 3	0 0	0 0	11
Mild MMSE	34.80% 8	27.30% 6	23.80% 5	2.90% 1	20
Moderate MMSE	21.70% 5	45.50% 10	38.10% 8	11.80% 4	27
Severe MMSE	8.70% 2	13.60% 3	38.10% 8	85.30% 29	42
Total residents	23	22	21	34	100



Main themes from Quality of Life Study



- 1) **Social contact** (family, staff and residents)
- 2) **Pleasurable activities** (structured and unstructured, outings and momentary pleasures)
- 3) **Attachment/adjustment** (feeling at home, missing home, and connectedness)
- 4) **Affect** (happiness, sadness/depression, loneliness)



What if anything that can be done to improve your quality of life?

“Yes get rid of the straps, the chains around you, that’s about all”

(Male 80, MMSE 4)



In context of Dementia Strategies what are other countries doing?

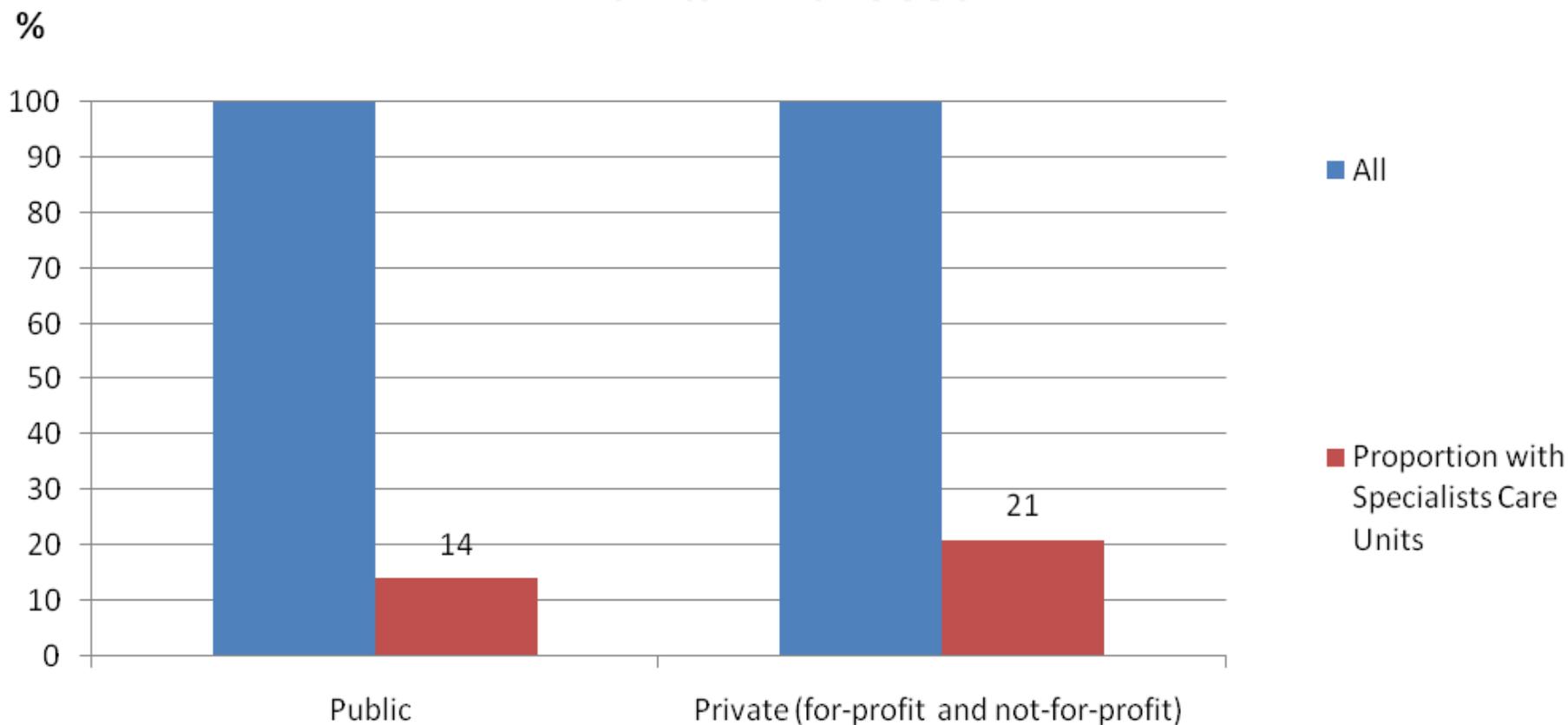
- **Norway:** the principle for residential facilities is 'small is beautiful'
- **The Netherlands:** Emphasis on small-scale, home-like living
- **France:** Adapting residential care for people with dementia and creating specialised care units for those with challenging behaviours; allocation of ring-fenced resources to achieve this
- **England:** living well with dementia in care homes – selected as one of four priority objectives where it is likely to show immediate benefits for people with dementia
- **Scotland:** Common standards of care for dementia across all care settings



What do we know about Ireland?

Findings on SCUs in Ireland based on Research Review

Proportion of public and private residential long-stay care units* with SCUs



Source: Cahill et al., 2012

Note: *The majority (approx. 75%) of residential long stay units in Ireland are private (for-profit and not-for-profit).



Some Questions

Have those involved in dementia specific training entered into open dialogue with HIQA inspectors?

How and where are the Supplementary Care Standards being used?

Does HIQA have a register of SCUs, if not why not?

Is anyone collecting information on dementia?

A Dementia Strategy for Ireland

- Strategy for Dementia embedded in Programme for Government by 2013
- Research review commissioned in 2011 and published 2012
- Setting up of Working Group August 2013
- Strategy now probably being postponed until early 2014





Discussion

- Have come a long way since 1990
- Now have National Quality Standards (Minimum)
- Supplementary Dementia Care Standards
- Review of Standards
- At good juncture to improve dementia care in nursing homes with HIQA review work and Dementia Strategy about to be launched

A decorative graphic at the top left of the slide consists of a grid of squares in shades of blue and grey, transitioning into a horizontal bar that is dark blue on the left and fades to light blue on the right.

Summary

But based on research findings and recent experiences Alzheimer's disease continues to remain invisible in residential care in Ireland

We need to **take dementia out of the closet, recognizing it is the core business of nursing homes** and open up the public debate about Alzheimer's disease

We need to resolve some of the tensions and contradictions that exist in current thinking about dementia

We need better information systems on dementia



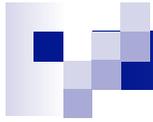
Conclusions

We must **create incentives** to appropriately reward the hard work and utter dedication of many professional staff working in this area

We must open up the dialogue between (i) inspectors and trainers and between (2) inspectors, nursing home providers and people with dementia and their family caregivers

We need to encourage positive risk taking which offers PwD more autonomy and opportunities to flourish not flounder

Most importantly we need to where possible listen to the voice of PwD



- “Do not go where the path may lead, go instead where there is no path and leave a trail”. [Ralph Waldo Emerson](#)

Useful websites

- www.dementia.ie
- www.livingwithdementia.tcd.ie

Thank you for listening



