Respite Care for Whom? Evaluating Two Different Models of Community Respite Care in Rural and Urban Ireland

Associate Professor Suzanne Cahill, Dr. Maria Pierce and Dr. Andrea Bobersky
The DSIDC and Trinity College Dublin Genio Annual Conference
Alexander Hotel Dec 12th

Overview

- The meaning of respite
- An evaluation of two GENIO CONSORTIA Projects
- Key findings
- Methodological choices and dilemmas
- Future directions

Definitions of Respite?

Any formal service designed to provide a break from the usual routine for the person with dementia and/or their carer (Bamford, 2014)

Temporary provision of care for the PwD at home or in an institution by people other than the primary caregiver

Respite describes diverse set of services which vary over a number of dimensions (Maayan et al, 2014)

Traditionally considered a service that physically or socially separates one party out for the benefit of the other (Armstrong & Shevellar, 2006).

Literature

- Respite can delay the need for nursing home care (Brodaty, 2009)
- It reduces caregiver stress (Zarit, 2014)
- Caregivers value respite, but take-up can be low (Lawton, 1989)
- Very few studies have evaluated both PwD and family caregivers experiences of respite
- Limited evidence of the effectiveness of different models and very few RCTs conducted on respite
- Recent Cochrane review – findings equivocal
- Recent Cochrane review of exercise and dementia (2013)

The Two Genio Projects

- Five Steps to Living Well with Dementia in South Tipperary

- Living Well with Dementia Initiative in Stillorgan Blackrock

Broad Aims

- To help PwD live at home for longer (prolong community care)
- Provide interventions enabling both caregivers and PwD to enjoy good quality of life

- Reduce or delay residential care
- Reduce the need for hospital care
- Overcome limitations of pre-existing services

Five Steps to Living Well with Dementia in South Tipperary

South Tipperary
Population of 88,432 in 2011
Population of PwD circa 1,054

THE 5 STEPS TO
Living Well
with Dementia

Estimated number of people with dementia in County South Tipperary, 2011

Age groups	Total Population (Census 2011)			Persons with dementia (estimated using EuroCoDe (2009) age/gender-related dementia prevalence rates)		
	Men	Women	Total	Men	Women	Total
30-59 years	18,419	18,015	36,434	37	18	55
60-64 years	2,381	2,347	4,728	5	21	26
65-69 years	1,867	1,809	3,676	34	25	59
70-74 years	1,438	1,468	2,906	46	56	102
75-79 years	1,054	1,189	2,243	74	90	164
80-84 years	707	914	1,621	103	150	253
85-89 years	316	616	932	66	176	242
90-94 years	108	223	331	32	99	131
95+ years	9	39	48	3	19	22
Total				400	654	1,054

(Pierce, Cahill & O'Shea, 2014)

Living well with Dementia Initiative Stillorgan Blackrock

Stillorgan Blackrock Population of 50,008 in 2011

Population of PwD circa 725

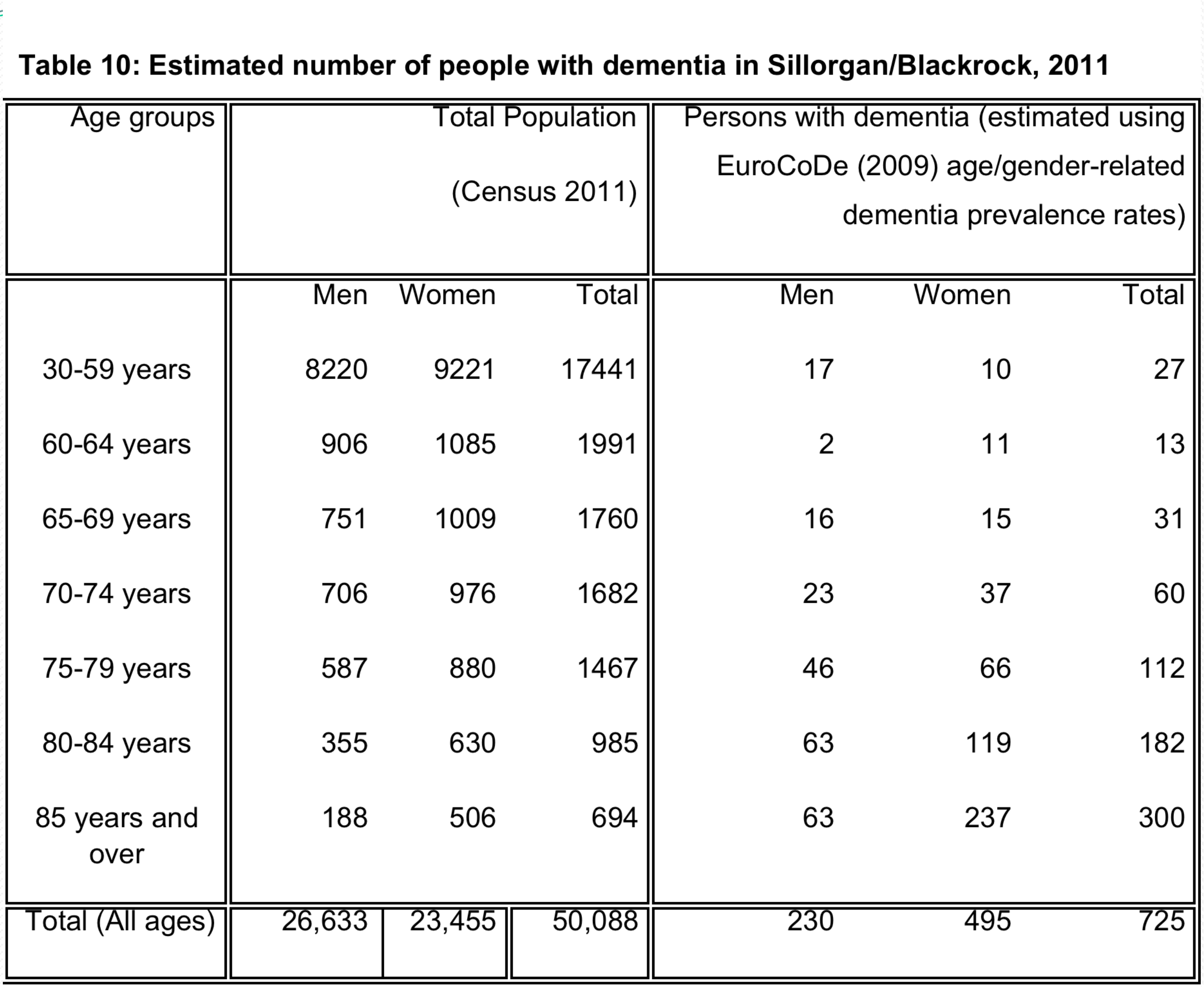


Table 10: Estimated number of people with dementia in Sillorgan/Blackrock, 2011

Age groups	Total Population (Census 2011)			Persons with dementia (estimated using EuroCoDe (2009) age/gender-related dementia prevalence rates)		
	Men	Women	Total	Men	Women	Total
30-59 years	8220	9221	17441	17	10	27
60-64 years	906	1085	1991	2	11	13
65-69 years	751	1009	1760	16	15	31
70-74 years	706	976	1682	23	37	60
75-79 years	587	880	1467	46	66	112
80-84 years	355	630	985	63	119	182
85 years and over	188	506	694	63	237	300
Total (All ages)	26,633	23,455	50,088	230	495	725

(Pierce, Cahill & O'Shea, 2014)

The Types of Genio Interventions

South Tipperary	Stillorgan Blackrock
Painting/Art/Cards	Exercise programme
Gardening	Transport support for same
Jigsaws	Social support
Life Story books	Formal Carer support
Shopping/visits to museums	

Principles underpinning both models

- Person-centered care
- Flexibility
- Choice
- Social inclusion
- Consistency
- Normalization
- Time limited
- Makes use of existing services
- Enables PwD to remain at home
- Client led
- Integration

Differences between Two Models

South Tipperary	**Stillorgan/Blackrock**
Rural	Urban
Individualised	Group
Old Age Psychiatry led	Nurse-led
Using pre-existing services	Training up new staff
Emphasis on opportunities for therapeutic input	Community awareness
PwD and Carer separated	PwD and Carer attend together, if wished

Research Methods

Qualitative research using in-depth conversational interviews with

- PwD (N= 17) &
- Family Caregivers (N= 20)

Use of validated scales

- The QoL AD
- The Caregiver Burden Scale

All research interviews audio-recorded and transcribed verbatim

Thematic analysis

Key Findings

- Overall FCs and PwD expressed high levels of satisfaction with new service models
- Clear evidence of how “respite” programmes contributed to improved quality of life for both
- Both Models aligned well with Person-centered care principles
- Key worker principle, flexibility and consistency highly valued by caregivers
- Both models promoted autonomy and complemented pre-existing services

Views on Respite

- “I loved it [painting] because see I used to knit and I could knit anything but now I can’t follow the pattern, so that was a terrible drawback … and so when she came I was delighted … I used to see people painting but it never occurred to me to do it …” (PwD 10 ST)

- ” Now when I think she can do the round trip (walking alone from own home to daughters) ….. And she’d walk to the PO and she’d walk back over to me ……Something must have been working because certainly like a year ago she was not capable of doing this) (FC, 9 SB)

Views on Respite

- “Oh it was flexible … and if I couldn’t have her come, I contacted them and said … Can we leave it for another two hours or whatever” (PwD, 9 ST)

- “There’s chat going on all the time and a chance afterwards to gather around with others attending and have tea and cake and socialise, a reward for your efforts something which I think is extremely important (PwD, 6 SB)

- She was brilliant. She was brilliant (DSW). Yeah, I’d be be waiting for the day for her… sure to the day that she is … she was coming, you were really looking forward. We’re always laughing, she’d put in good humour (PwD 8 ST)

Views on Respite

… she likes talking about it you know the independence … it makes her feel like what normal people do … so it makes her feel a little important and independent and it gives her a reason to get dressed, to spruce herself up a little bit more in the mornings and oh it’s empowering … I really believe that (FC 9, SB)

Carers don’t normally have the time to sit and talk or sit and play music so its kind of different in the sense that they (Respite support workers) can provide that” (FC 4, ST)

Views on Respite

- She was easy to talk to, you know, I always wondered what I'll have to say today to her … I think, you know, there was no pressure as such … I didn't feel any pressure and that I could say what I had to say (PwD 7, SB)

Views on Respite

- We felt that even for them (DSW) to come and sit with Dad to give him a drink, to give him some yoghurt, to play music .. It did really help us as the carers (FC 4, ST)

- People don’t want things like for hours on end. They just want kind of a maybe two hour thing, - its enough and that enough an activity for a day (FC 8, SB)

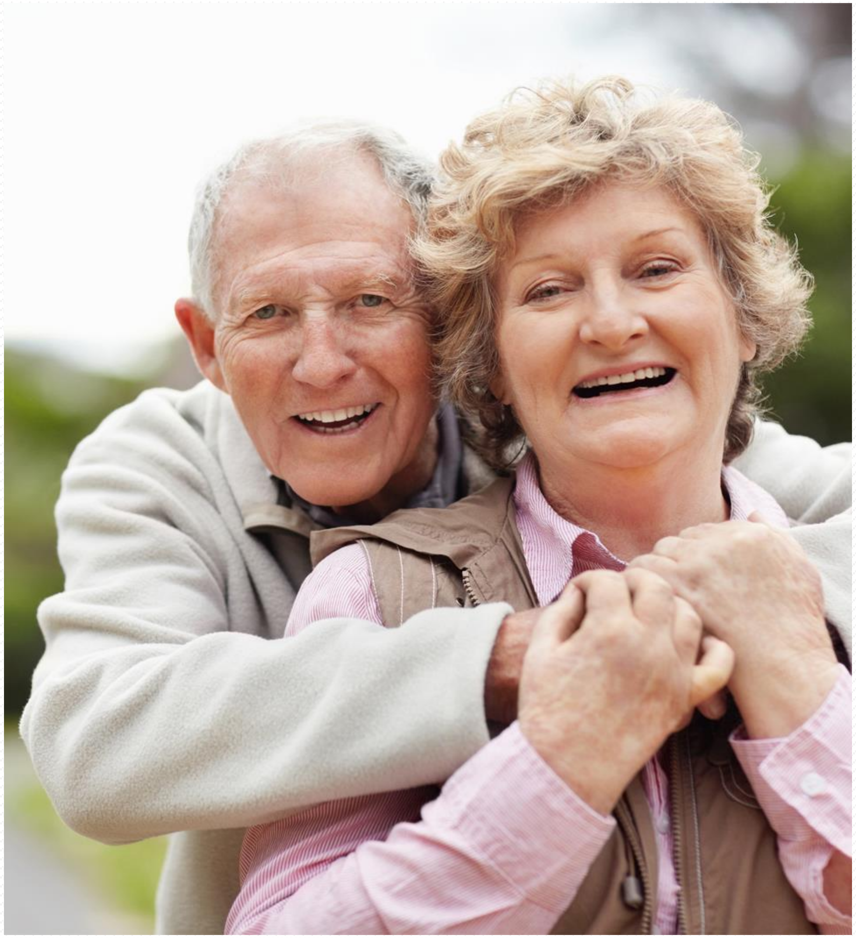
Quality of Life & Carer Burden Results

Scores	South Tipperary	Stillorgan Blackrock
Mean Caregiver Burden	32 (20-26)	29 (12-57)
Mean QoL rated by Family Caregiver	29 (22-34)	34 (28-40)
Mean QoL rated by PwD	34 (24-34)	34 (29-38)

Views on Respite

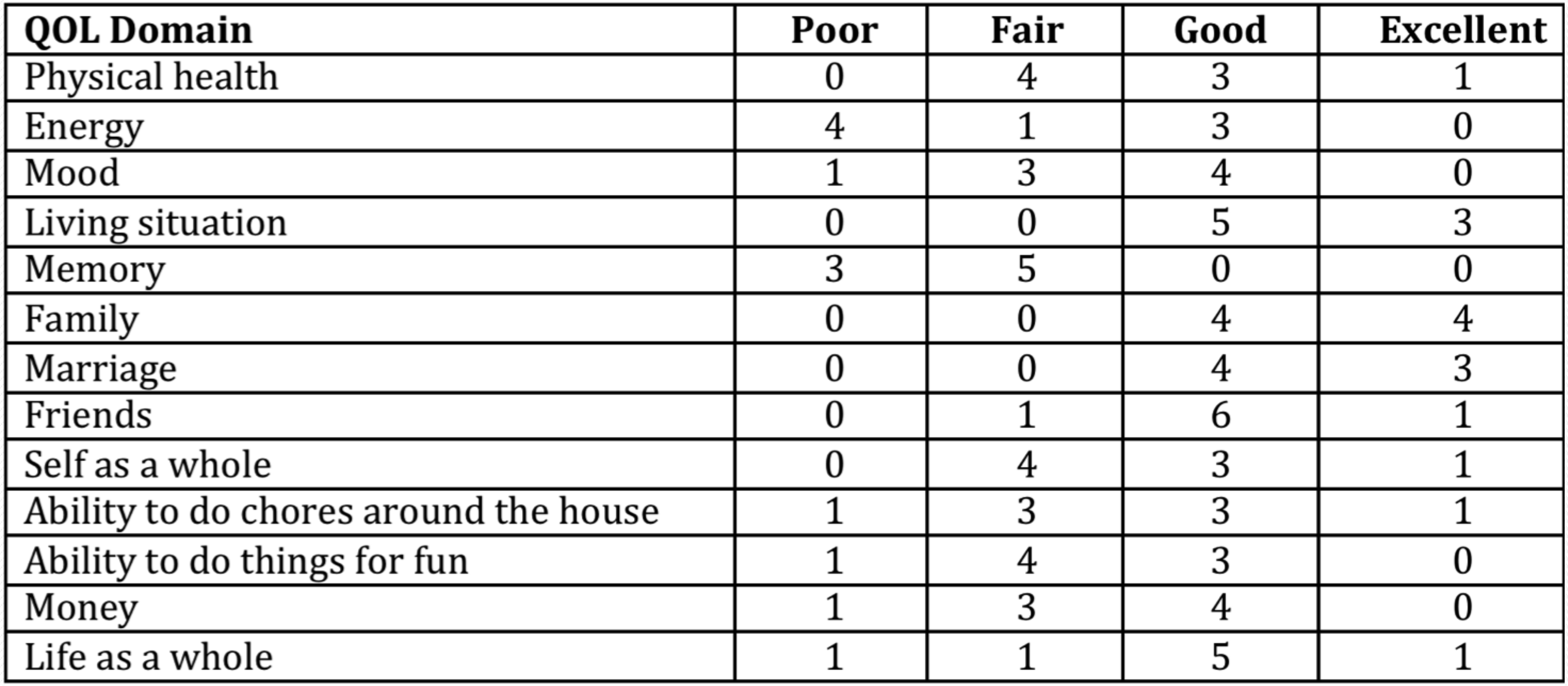
"And to know that he's there, and there's someone with him, he's being stimulated, the relief that is, its incredible" (FC 2 ST)

"They make available information that otherwise I wouldn't have the time to access. I'm just too busy" (FC 10, SB)



Example of Responses of PwD QoL AD

(N=8) South Tipperary



QOL Domain	Poor	Fair	Good	Excellent
Physical health	0	4	3	1
Energy	4	1	3	0
Mood	1	3	4	0
Living situation	0	0	5	3
Memory	3	5	0	0
Family	0	0	4	4
Marriage	0	0	4	3
Friends	0	1	6	1
Self as a whole	0	4	3	1
Ability to do chores around the house	1	3	3	1
Ability to do things for fun	1	4	3	0
Money	1	3	4	0
Life as a whole	1	1	5	1

The scale fails to address issues such as independence, confidence normality –(Diaz, 2013) issues important to many people in the sample as reflected in qualitative data.

Examples of Responses to Caregiver Burden (N=19)

- 100% either sometimes or always fearful of the future
- 68% report that because of caring don’t have enough time for self
- 52% believe their health has suffered due to caring
- 31% claim they have lost control of their lives due to caring
- Most (73%) don’t feel embarrassed, angry(63%) or that they don’t have sufficient money to care (78%)

Limitations

- Small sample sizes also biased at both sites, findings need to be cautiously interpreted
- No standard diagnostic tools used for assessment
- No pre-post intervention data available on outcome measures
- No information collected from service providers
- Timing of data collection not standardised

Future Directions

- Both community respite initiatives have been significantly redesigned to be more responsive to wide range of individual needs
- New study using similar instruments but changing design to capture pre-intervention post-intervention data?
- Intention to target particular “at risk” groups e.g. those living along those with young onset dementia?
- Challenges of attempting to capture experiences of different interventions

Concluding Remarks

- Creative models were successful in providing new and at times re-igniting old recreational & social activities for the PwD and providing carers with breaks
- Respite interventions have made dementia much more visible in communities linking community, voluntary and statutory groups
- One-to-one support may be costly financially but can confer enormous social, emotional and psychological benefit in short term

"It's so important to get a person's name and to feel that they listened to what you said and that you don't have to repeat the story again. In the end I got a Case Worker and my whole life changed … I wanted to fall down and kiss her feet"!

(from Robinson et al., 2012: 205)

Thank You !

Email: cahillsu@tcd.ie

Website: www.dementia.ie

Website: www.livingwithdementia@tcd.ie

The ATLANTIC Philanthropies

living with dementia

School
of Social Work
and Social Policy