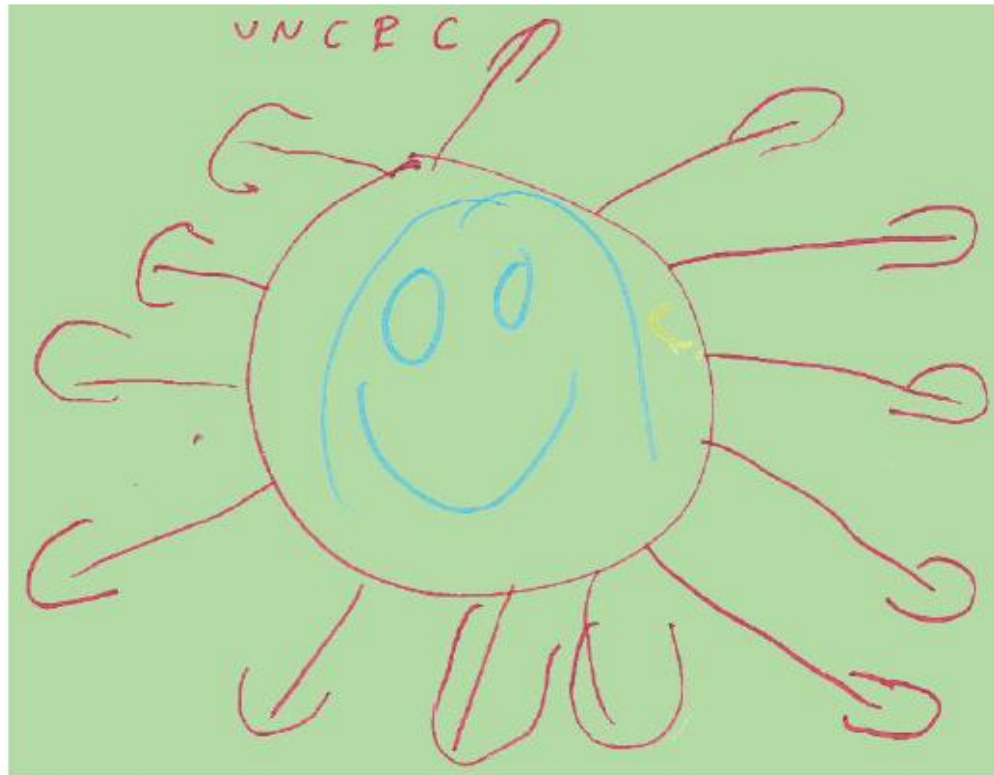


Emotional Well-being of Disabled Young People: Our Story



Improving the Well-being of Disabled Young People



Drawing by Olivia, aged 13

Dr Grace Kelly

Dr Berni Kelly

Professor Geraldine Macdonald

March 2016



Age and gender of participants

Age	Male	Female	Total
10		1	1
12-18	15	12	27
19-24	7	2	9
TOTAL	22	15	37

Theoretical context

Subjective Well-being	Hedonic		Mitigating factors (personality, environment etc.)
	<i>Evaluation</i>	Overall Life Satisfaction	
	<i>Experience</i>	Positive affect: (e.g. happiness, joy, pride, fulfilment) Negative affect: (e.g. sadness, anger, disappointment, anxiety, fear)	
	Eudaimonic		
	<i>Psychological well-being</i>	Purpose in life	

Positive emotions & common sources

Emotions	Common sources
Happiness	Family achievements, family time together, good peer relations, having a pet
Pride	School achievements, sporting achievements, personal development
Confidence	Having a positive attitude, sense of independence, good communication with others

Negative emotions & common causes

Emotions	Common causes
Worry	Future job prospects, unfulfilled aspirations, family income
Guilt	Feelings a burden, parental health
Sadness	Dependence, poor communication, bullying, absence of choice, low self-esteem
Anger	Lack of understanding, transport, bullying, absence of choice, inaccessibility, unprofessional practices, not being listened to, disrespect

OUR STORY

<https://vimeo.com/191633051>



OÉ Gaillimh
NUI Galway



Therapeutic lying: Is it an acceptable approach to use with people with dementia?

Presenters: Dr Pauline Meskell, Dr Una Lynch & Professor Dympna Casey

Other Research team members: Murphy, K. Cooney, A. Gannon, M. Houghton, C. Hunter, A. Jordan, F. Smyth, S. Devane, D.

Background and why important

- More than 60,000 people with dementia living on the island of Ireland.
- Predicted that :
 - By 2041 -140,580 people with dementia living in the South (Cahill *et al.* 2012)
 - By 2051 60,000 people with dementia in the North (The Department of Health, Social Services and Public Safety 2011)
- We need to ensure that people with dementia and their carers are supported in the best way possible.
- In 2014 the Centre for Ageing Research in Ireland (CARDI) commissioned NUIG and Sonrisa Solutions Limited in Banbridge Co Down to carry out a cross-border research study, which would address the question: **“What is the best approach to take when a person with dementia says something that is false?”**

Aim & Objectives

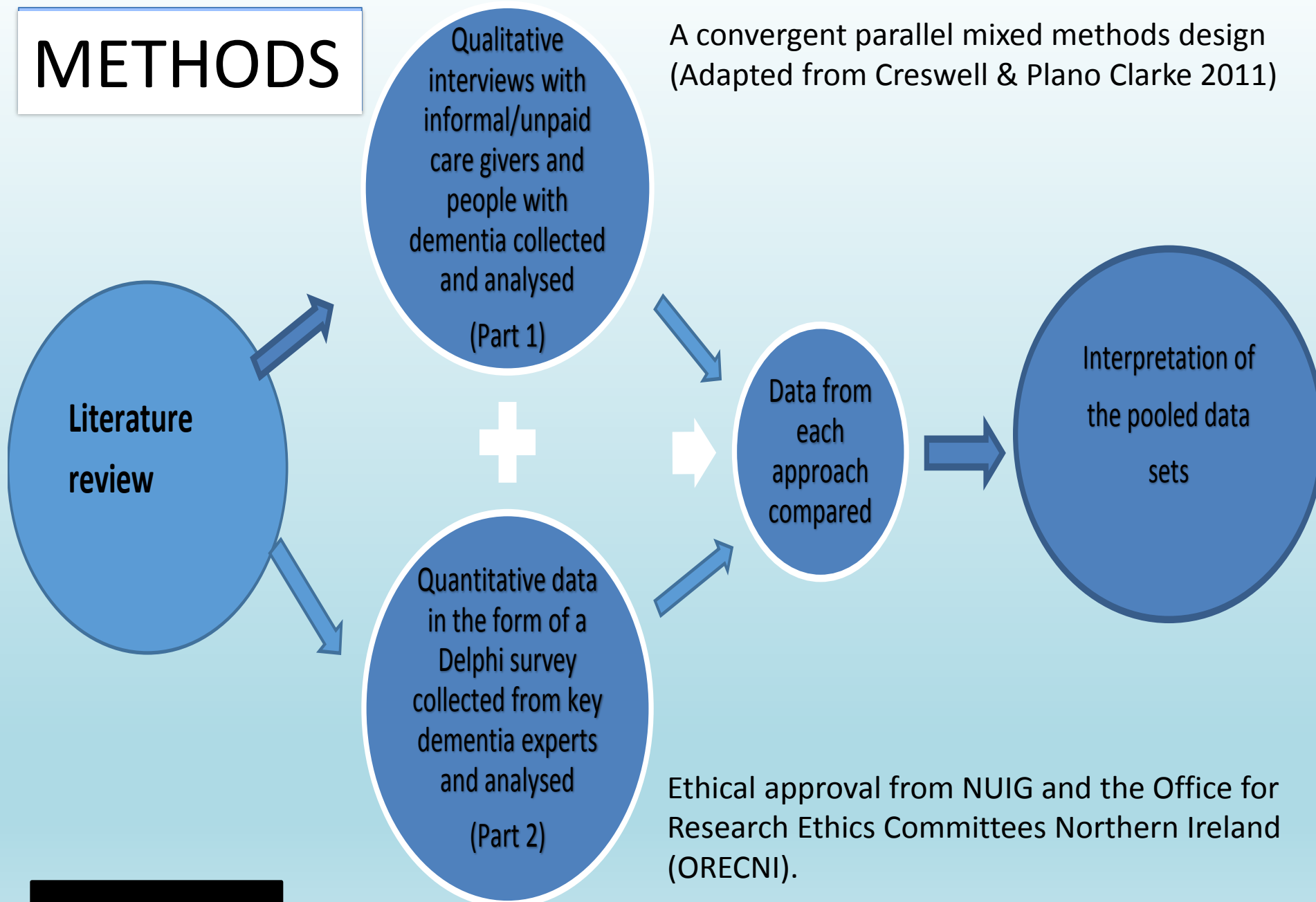
Aim: to generate guidelines for carers on the best approach to take for people with dementia when they ask questions or make statements that are false

Objectives:

- Review the evidence on the preferences of people with dementia, particularly those who can make informed decisions at the earlier stages of their diagnosis.
- Summarise the most recent research in the field of dementia e.g. therapeutic lying, validation therapy
- Examine the practical implications for those health professionals who adopt alternatives to correcting a person with dementia, including a review of codes of conduct.

METHODS

A convergent parallel mixed methods design
(Adapted from Creswell & Plano Clarke 2011)



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PHASE 1

PHASE 2

Ethical approval from NUIG and the Office for Research Ethics Committees Northern Ireland (ORECNI).

Phase 1 Literature Review

- A comprehensive review of the literature on therapeutic lying, validation and reality therapy was undertaken,

Reality Orientation & Validation Therapy

- **RO**: aim to improve cognition by facilitating orientation to reality with the aid of a variety of props, such as, orientation boards, discussion of recent events etc.
- Cochrane Systematic Review (Spector *et al.* 2000) -some evidence that RO improved cognitive functioning and behaviour in older people with dementia but these positive effects may be short lived.
- Overtime subsumed under the umbrella of cognitive stimulation therapy (Woods *et al.* 2012).
- **VT**: based on accepting the reality and the personal truth of a person's experience and it puts emphasis on the emotional content of what the person with dementia is expressing rather than what is being said (Feil, 1992)
- Qualitative studies -promotes better communication and interaction between the carer and person with dementia; it has a positive effect on behavioural symptoms and enhances the quality of life of both carer and person with dementia (Bleathman & Morton, 1988; Babins, 1998).
- However Cochrane systematic review (Neal & Wright, 2003), as yet, there is insufficient evidence to support the use of validation therapy for people with dementia.

Therapeutic lying (Fibbing or 'white lies')

- Rather than the reorienting a person with dementia, you 'go along' with the person's disoriented state and 'lie' to avoid conflict and reduce the distress of the person with dementia (Shellenbarger 2004).
- Underpinned by empathy and compassion and this distinguishes therapeutic intent from harmful intent (Green 2015, p13).
- **Staff-** reported they had lied to people with dementia when it was deemed to be in the best interests of the person despite the fact that professional guidelines and codes of conduct do not support lying to patients irrespective of cognitive status (Culley *et al.* 2013; Tuckett 2012, Elvish *et al.* (2010); James *et al.* 2006)
- **People with dementia-** lying was acceptable if it was in the best interest of the person, but not if it caused distress or devalued the person (Day *et al.* 2011)
- Kartalova-O'Doherty *et al.* (2014) literature review
- No clear consensus regarding the use of TL / 'white lies'
- The level of dementia had great relevance in the use of TL
- **Key message** the intention behind the 'white lie' in that an intention to cause harm to the person with dementia is never acceptable
- However few published studies have explored the use of TL in caring for people with dementia- 'grey literature'

Phase 2 : Part 1 Qualitative

- A qualitative descriptive approach, (Sandelowski 2000)
- 3 focus groups with people with dementia (n=14)
- 3 focus group interviews with carers (N=18)
- Interview guide developed from the literature and expertise of the authors
- All interviews were tape recorded and transcribed verbatim.
- Qualitative content analysis- initial open coding, collapsed into key categories;
- The criteria identified by Lincoln and Guba (1985) were used to ensure and maintain rigor.

Demographics of PWD

Characteristic	N(%)	Characteristic	N(%)
<u>Gender</u>		<u>Highest Level of Education Attained</u>	
Male	5(37%)	No formal education	0(0%)
Female	9(63%)	Secondary Education	2(14%)
<u>Age group</u>		Third Level – Non Degree	2(14%)
40-49	2(15%)	Technical/Vocational	4(30%)
50-59	0(0%)	Third Level-Degree or above	3(21%)
60-69	2(15%)	Professional Qualification	2(14%)
70-79	6(46%)	Primary Education	1(7%)
80+	3(24%)		
<u>Number of years with memory loss</u>			
Less than 1 year	1(9%)		
1-3 years	6(55%)		
4-6 years	4(36%)		
7+ years	0(0%)		

Characteristic	N (%)	Characteristic	N (%)
<u>Age group</u>		<u>Years caring for a PWD</u>	
20-29	0(0%)	0-4	11(69%)
30-39	0(0%)	5-9	3(19%)
40-49	1(6%)	10-14	2(13%)
50-59	8(44%)	15-19	0(0%)
60-69	2(11%)	20-24	0(0%)
70+	7(39%)	25+	0(0%)
<u>Gender</u>		<u>Highest Level of Education Attained</u>	
Male	5(28%)	No formal education	0(0%)
Female	13(72%)	Secondary Education	7(39%)
<u>Supports for caring for a PWD</u>		Third Level – Non Degree	2(11%)
Respite	3(20%)	Technical/Vocational Qualification	0(0%)
Day Care	0(0%)	Third Level- Degree or above	5(28%)
Professional carers	2(13%)	Professional Qualification	1(6%)
Family/other carers	7(47%)	Primary Education	2(11%)
Other	3(20%)	Post Leaving Cert	1(6%)
		Other	0(0%)

People with Dementia



*Acceptability
of Lying
Continuum*

*Respectful
Lying*



PWD: *Acceptability of Lying Continuum*

- Ranged from “not acceptable under any circumstances” to “*acceptable in certain circumstances*”.
- Minimising truth-related distress was identified as the sole context when lying may be acceptable.
- Participants agreed that if the person was at a “bad” stage then it was more acceptable to lie to minimise truth-related distress.
- They equated the stage of dementia with awareness, in that if the person was likely to become aware that they were being lied to it was never acceptable to lie.

“... I don't care what the situation is it's not acceptable.” (FG3).

“R1: I think a lie is not acceptable at any time.

Int: What do you say (Name)?

R2: I know that it's not acceptable, I know it's not acceptable but you're only upsetting the person more with what you're telling them.” (FG1)

- *“...we're all different here. And personally at the stage that I'm at if I hear about the death of somebody or something like that there I would appreciate being told ... because I'm at that stage.” (FG3)*

PWD: *Respectful Lying*

Participants explained that their concern about being deceived was coloured by their experience of living with dementia. The experience of living with dementia made them feel vulnerable and at risk of losing control and autonomy

Participants made clear that respecting the person's individuality and personhood should be the fundamental principle guiding decisions as to what action to take.

"There's nothing as bad as an individual living with confusion ... to experience that ... Confusion in anybody's mind, in my mind anyway it's so soul destroying, it's unreal when I see a thing on the television that I know that I should know but it's not there. I can't lift the guitar in my hand that I used to love doing because the chords are not there anymore, I can't remember them... And from the outside person would really need to understand the person with dementia considerably before they would make any moves. Everybody is an individual and that's what it's about." (FG1)

"... it should be handled with kid gloves... But again it comes down to the individual. And to know certainly what the individual's reaction is going to be before you go there ... so it's knowing him or knowing her, the relationship with the carers and the family and doing your homework before you go there, you know." (FG3)



Carers

*Acceptability
of Lying
Continuum*

*“Approaches to
managing
mistakes”*

*“empathetic
deception”.*



Carers: *Acceptability of Lying Continuum*

Also viewed the acceptability of lying as a continuum ranging from “never acceptable” to “acceptable under certain circumstances”.

- expressed concern that lying could cause mistrust, impacting negatively on their relationship with the person with dementia.
- Others viewed the decision to lie as relatively straightforward. Minimising truth-related distress was one reason for opting to lie or avoid the truth.

“I do have qualms... So I have difficulty lying to {name of person} because neither of us is a liar, you know and truth has always been very important to both of us. So I have difficulty with it, especially if it’s taking him further into where I feel is confusion....” (FG2 Carers)

“I’d a recent one now where mother was asking for Dad ... he’s not sitting in his usual chair. Now he’s dead three years. So I kind of thought well the last time I told her that he was dead we had to go through the whole grieving process and I got terribly upset as well. So I thought well OK this time now I’ll just kind of go with the flow and I’ll try and put her off a little bit and I just said ‘oh sure he must be out’... But I just didn’t want to put her through the whole grieving process again. ... (FG3 Carers)

Carers: Acceptability of Lying Continuum

In relation to the acceptability of formal carers lying, participants felt that in certain circumstances it is necessary.

They believed that formal carers should act in way that is appropriate to the person (assumes knowing the person).

"...if a carer comes in the door? I'll tell her where mother is at and I'll tell her what's her reality at the minute ... and try and go along with that if you can. And I'll give her little backdrops if it's not working. And I'll expect that they'll respect that, I would be very disappointed if somebody came along cold or whatever and said something that would bring mother too much to her reality ..." (FG3 Carers)

- *"My father has been in respite, you know and I accepted that the people who work in those places have to (tell a therapeutic lie) because they haven't got the time apart from anything else to kind of get into discussions about what is the reality for this person. So I think it's kind of acceptable in that environment because I don't understand how it can work otherwise. But there is a disconnect then when the person comes home from respite."* (FG2 Carers)

Carers: Approaches to managing

mistakes

Carers used a range of strategies to manage the situation when the person made a mistake or became confused

- “I know at the beginning we were a bit corrective of mother but I have been to some of the seminars and things like that and I was talking to my wife who hadn't been to those and she was more corrective and I was trying to pull her back. Letting it go really.*”

“I remember when Dad would be asking, I would distract him, he'd say 'where is mum', I'd kind of switch it around quick and I'd say something completely (different), you know” (FG1 Carers)

“With my mother, she regularly wanted to go home to her mother who was long gone...and I'd say 'I just have to collect something', just excuses that I had to go somewhere... but there were times when I would have said to her that you know 'that's not right, that's not correct', but I think you have to gauge, depending on what they're able for at the time.” (FG2 Carers)

Carers: Empathetic Deception

- The strategy of “going with” the person, i.e. not challenging them (except if it put the person at risk) was used with empathy and not to deliberately deceive.
- The “lies” they told were shaped by their knowledge of the person and designed to reassure them
- The personhood and individuality of the person with dementia was stressed.

“I don’t understand how there could be hard and fast guidelines because it’s going to be different depending on what type of dementia you have ... and the relationship with the person.” (FG2)

“(I have to be creative but) because it’s my mother...I know what she thinks ... So if she goes well ‘where is (Daughter’s name)’ and I can know what she will accept about where (she) is? ... She will only accept that my brother is working, he is not allowed to be enjoying himself.

So you tell a white lie.

Yes I do. (FG1 Carers)

“... all his family are living in different parts of the world and he forgets that they’re not just down the road. So I just don’t contradict anymore. I just say ‘she’s coming to see you in a few weeks’ or you know... because it reassures him that they are coming. And yeah he’ll forget the next day but when they do come he’s delighted.” (FG2 Carers)

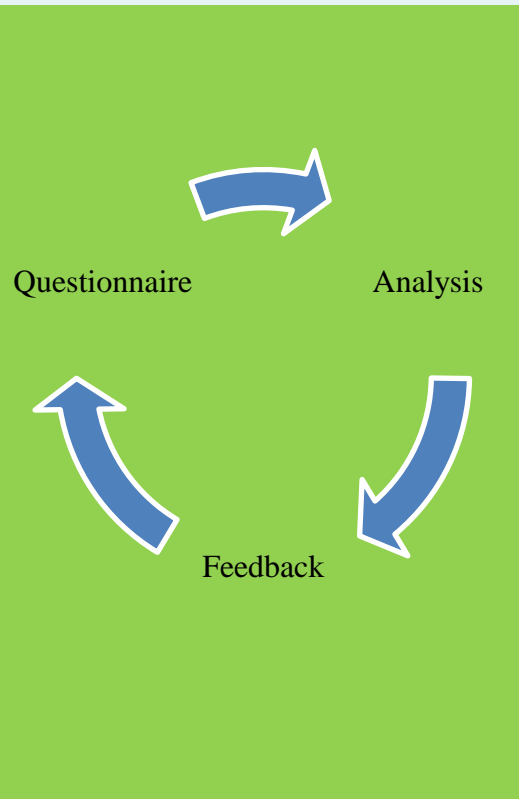
To Summarise: PWD & Carers

- Both groups agreed
 - that lying is not acceptable in certain circumstances, for example, when the person is aware and striving to retain control and autonomy
 - that therapeutic lying was appropriate if it clearly benefited the person i.e. diminished or allayed distress or agitation. However, the nature of the lie as well as the intention matters
 - the importance of maintaining the person's dignity and respecting his/her personhood
 - The risk-benefit of therapeutic lying should be assessed in context of the individual needs

Phase 2:Delphi



Delphi process



Round 1

Structured questionnaire
Formulation of statements
Based on literature
Participants rank statement
agreement/disagreement
Researcher summarises
rankings & reformulates
questionnaire

Round 2

- Same questionnaire as R1 inc. feedback
- Participants rank statement agreement/disagreement in light of group opinion
- Researcher summarises rankings & reformulates questionnaire

Round 3

Summary of group responses/individual responses
Re-rank with rationale

Consensus

Levels of consensus

Consensus	Definition
High	70% of ratings in one agreement category or 80% in two contiguous categories
Moderate	60% of ratings in one agreement category or 70% in two contiguous categories*
Low	50% of ratings in one agreement category or 60% in two contiguous categories*
None	Less than 50% of ratings in one agreement category or less than 60% in two contiguous categories*
	*Contiguous agreement categories are: 1 and 2 or 3 and 4

Source: deLoe (1995)



Demographics

Variable	N=54	%
Geographical spread		
Ireland	31	57.4
United Kingdom	20	37.0
Australia	3	5.6
Age group		
24-34	3	5.5
35-44	18	33.3
45-54	22	40.7
55-64	9	16.8
65+	3	3.7
Gender		
Male	10	18.5
Female	44	81.5

Place of work		
Acute hospital	10	18.5
Community care	17	31.5
Educational Institution	10	18.5
Other	17	31.5
Current work setting		
Mental Health	4	7.4
Education	11	20.4
Acute Care	7	13.0
Long stay/residential Care	10	18.5
Nursing	9	16.7
Medicine	4	7.4
Public Health	2	3.7
Administration	2	3.7
Social care	3	5.4
Psychology	1	1.9

Level of expertise: 1-10 scale, All >5
77% (n= 42) rating themselves as 7 or above.

Delphi round 1

The objectives of round 1 were to:

- Obtain the panellists perceptions on the best approaches to take when a person with dementia makes statements that are false
- Allow panellists the opportunity to provide reasons for ratings
- Allow panellists to rate their own perceived level of expertise
- Obtain demographic details of panellists



Survey Methodology



Round	Invited	Q's sent	Q's comp.	RR's
Round 1	65	54	47	87%
Round 2	47	47	43	91.4%
Round 3	43	43	40	93%

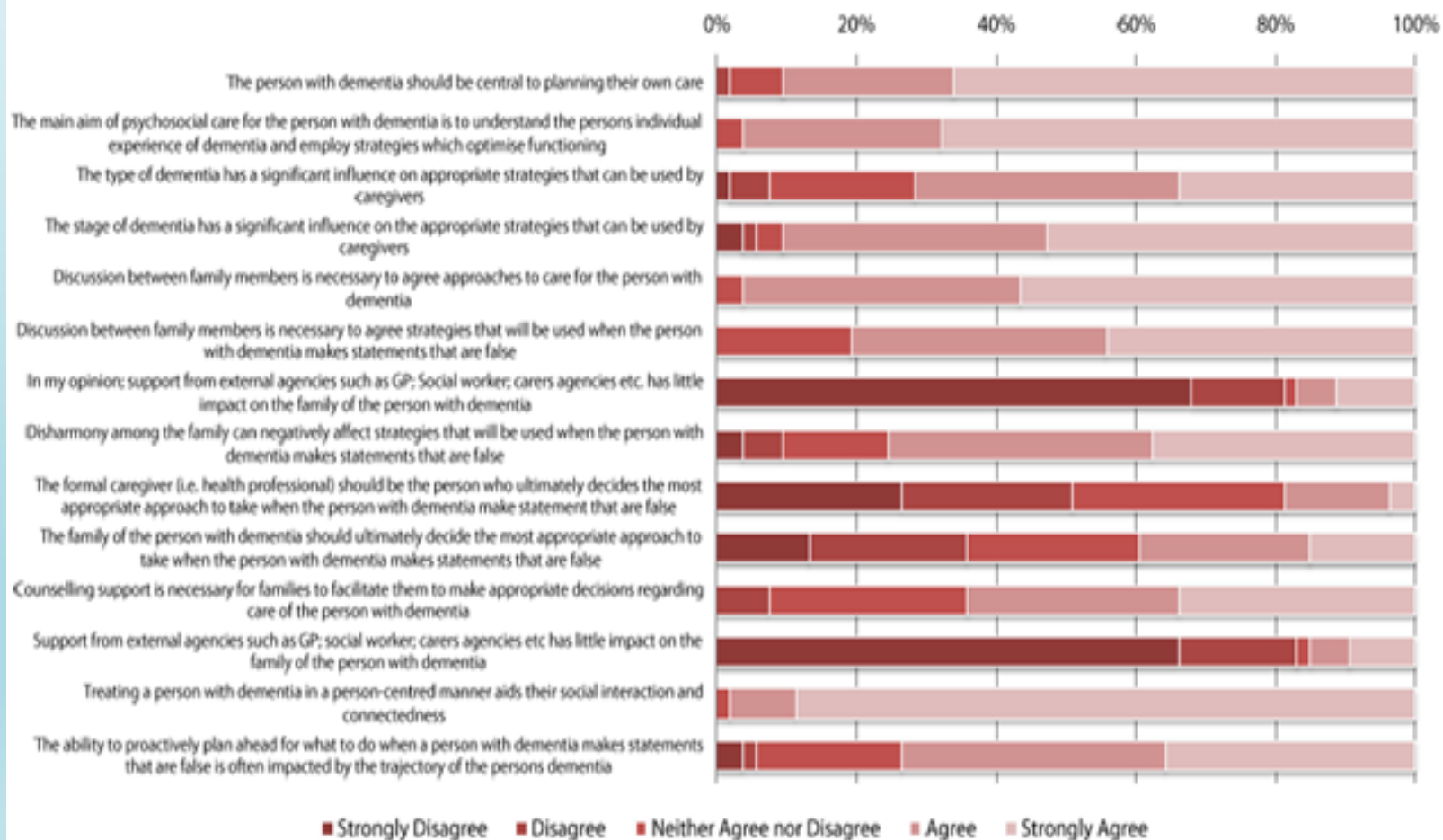
Example of round 1 analysis

Table 5: Mean and Standard Deviation ratings of Section A, Round One⁴

Section A: Care Environment Influences (9 = strongly agree, 6= agree, 3= disagree, 1=strongly disagree)	Mean	SD
A1. The person with dementia should be central to planning their own care	8.4	1.2
A2. The main aim of psychosocial care for the person with dementia is to understand the persons individual experience of dementia and employ strategies which optimise functioning	8.5	.95
A3. The type of dementia has a significant influence on appropriate strategies that can be used by carers	7.3	1.8
A4. The stage of dementia has a significant influence on appropriate strategies that can be used by carers	8.0	1.6
A5. Discussion between family members is necessary to agree approaches to care for the person with dementia	8.3	.97
A6. Discussion between family members is necessary to agree strategies that will be used when the person with dementia make statement that are false	7.9	2-3
A7. In my opinion, support from external agencies such as GP, Social worker, Carers agencies etc. has little impact on the person with dementia	3.0	3.0
A8. Disharmony among the family can negatively affect		

Example of R 1, Sec. A % agreement analysis

Figure 3 Round One Section A: Care Environment Influences



Section A Round 1: Example % agreement (High Consensus)

- Treating a person with dementia in a person-centred manner aids their social interaction and connectedness (98%, A13)
- The main aim of psychosocial care for the person with dementia is to understand the persons individual experience of dementia and employ strategies which optimise functioning (96%, A2)
- Discussion between family members is necessary to agree approaches to care for the person with dementia (96%, A5)
- The stage of dementia has a significant influence on the appropriate strategies that can be used by caregivers (94% ,A4)
- The person with dementia should be central to planning their own care (91%, A1)
- Discussion between family members is necessary to agree strategies that will be used when the person with dementia makes statements that are false (81%, A6)

Round 2



The purpose of round 2 was to provide panellists with :

- Feedback on the group rating of items
- the opportunity to reflect on their original answers in light of feedback on the group ratings

Feedback

- Panellists were able to view the group mean rating of each item and the percentage rating of each scale item.
- Panellists were given a summary of qualitative comments provided by panellists who provided rationale for their choices in round 1.

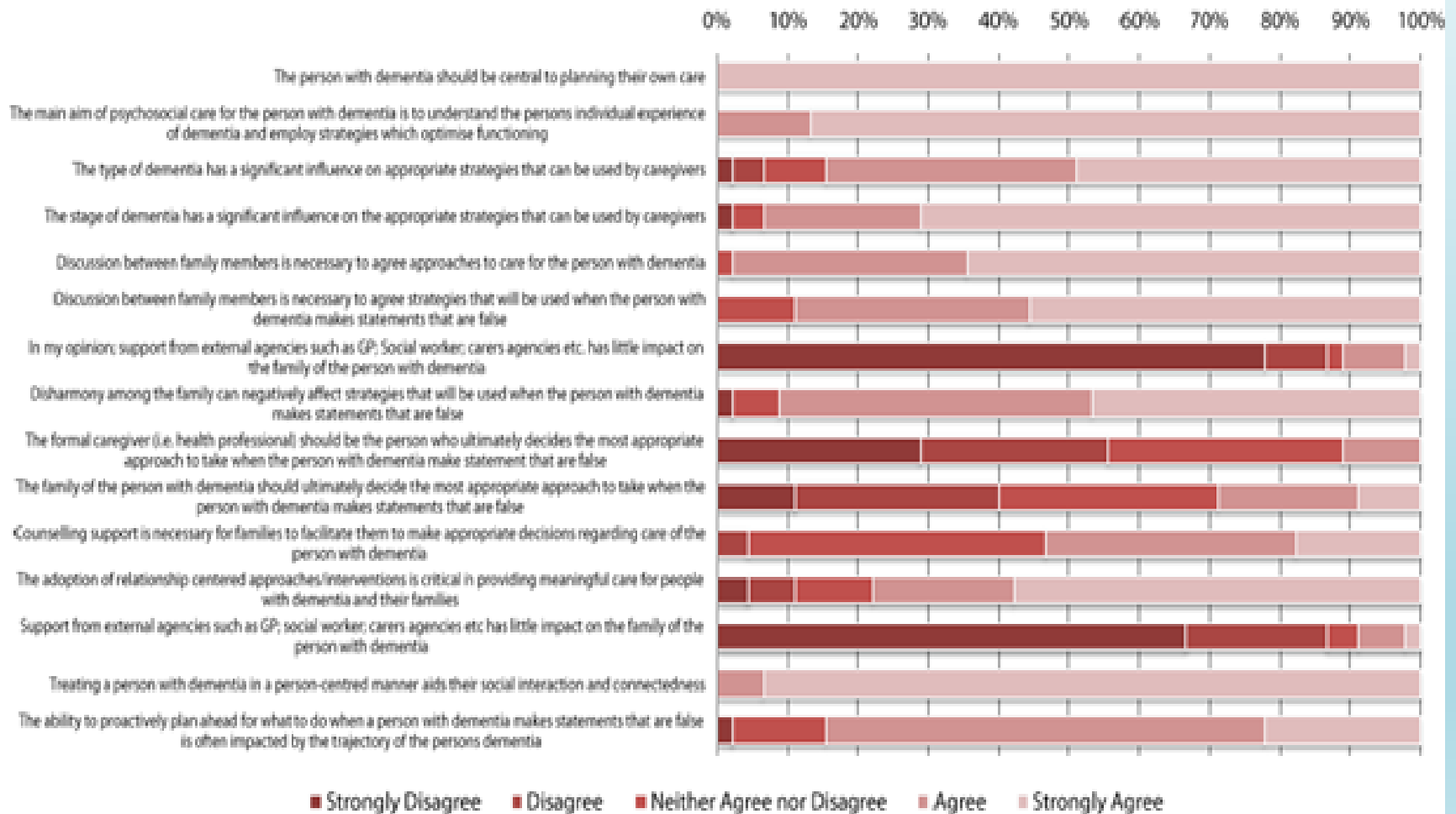
Example Round 2 analysis

Table 10: Mean ratings of Section A: Round One & Round Two

Section A: Care Environment Influences (9 = strongly agree, 6= agree, 3= disagree, 1=strongly disagree)	R1 Mean	R2 Mean
A1. The person with dementia should be central to planning their own care	8.4	8.5
A2. The main aim of psychosocial care for the person with dementia is to understand the persons individual experience of dementia and employ strategies which optimise functioning	8.5	8.8
A3. The type of dementia has a significant influence on appropriate strategies that can be used by carers	7.3	7.8
A4. The stage of dementia has a significant influence on appropriate strategies that can be used by carers	8.0	8.4
A5. Discussion between family members is necessary to agree approaches to care for the person with dementia	8.3	8.5
A6. Discussion between family members is necessary to agree strategies that will be used when the person with dementia make statements that are false	7.9	8.1
A7. In my opinion, support from external agencies such as GP, Social worker, Carers agencies etc. has little impact on the person with dementia	3.0	2.2
A8. Disharmony among the family can negatively affect strategies that will be used when the person with dementia make statements that are false	7.5	8.0
A9. The formal carer (i.e. health professional) should be the person who ultimately decides the most appropriate approach to take when the person with dementia make statements that are false	4.4	3.8

Example of R2 Sec A, % agreement

Figure 8: Round Two, Section A: Care Environment Influences



Round 3

The purpose of Round 3 was to:

- Provide panellists with feedback on agreement levels of statements in Rounds 1 and 2.
 - Introduce action statements derived from statements in Rounds 1 and 2.
 - Provide panellists with the opportunity to reflect on the action statements in light of strength of group opinion.
- Provide panellists with the opportunity to indicate importance level of action statements
 - Utilise ratings on action statements to identify strategies that will inform a best practice approach when people with memory problems make statements that are false.



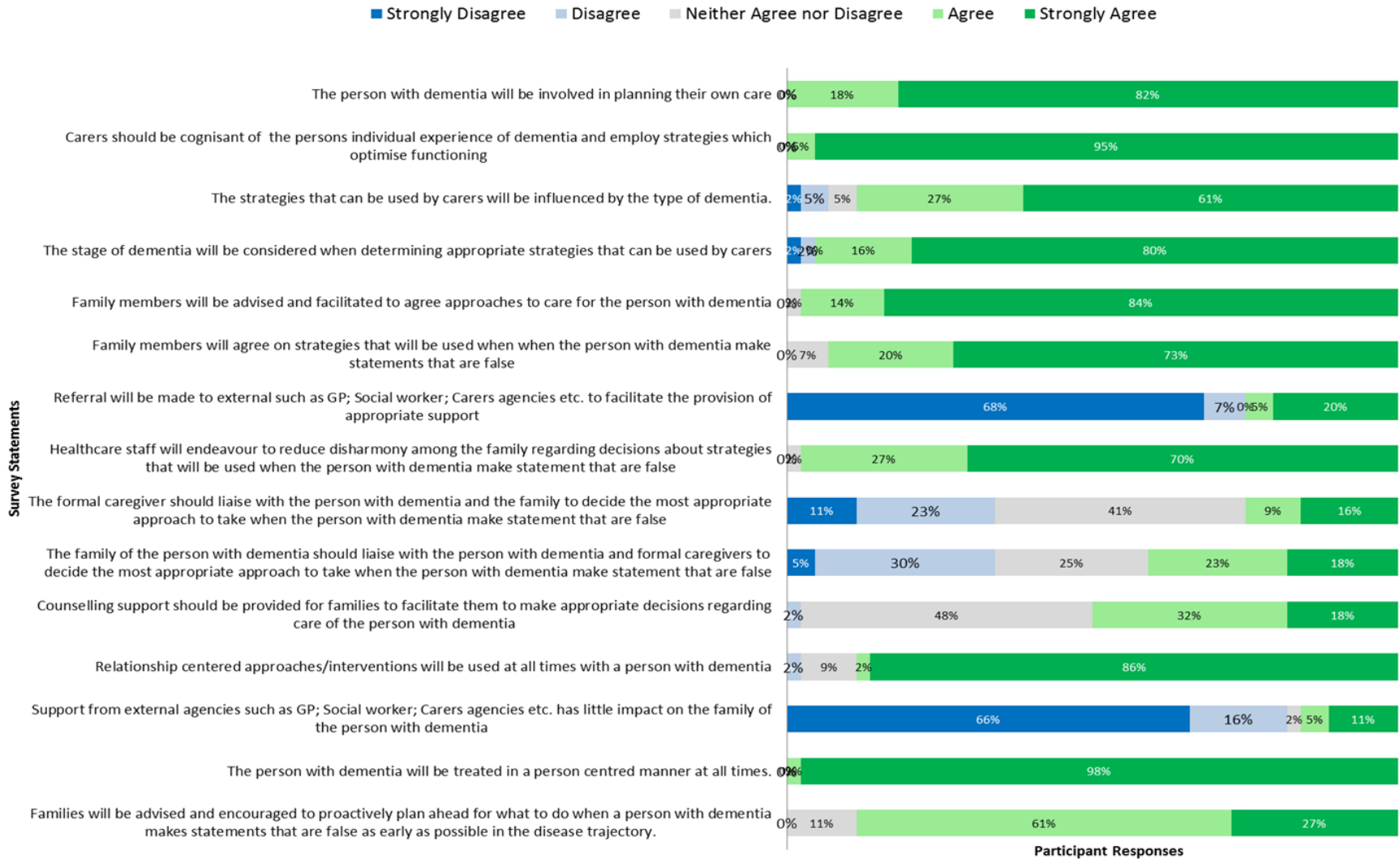
Example of R3, analysis mean & S.D.

Table 15: Mean and Standard Deviation ratings of Section A, Round Three

Section A: Care Environment Influences (9 = strongly agree, 6= agree, 3= disagree, 1=strongly disagree)	Mean	SD
A1. The person with dementia will be involved in planning their own care	8.8	0.4
A2. Carers should be cognisant of the persons individual experience of dementia and employ strategies which optimise functioning	8.9	0.3
A3. The strategies that can be used by carers will be influenced by the type of dementia.	8.0	1.7
A4. The stage of dementia will be considered when determining appropriate strategies that can be used by carers	8.5	1.5
A5. Family members will be advised and facilitated to agree approaches to care for the person with dementia	8.7	0.7
A6. Family members will agree on strategies that will be used when the person with dementia make statements that are false	7.5	0.9
A7. Referral will be made to external such as GP; Social worker; Carers agencies etc. to facilitate the provision of appropriate support	3.2	3.3

Example of round 3 % agreement analysis

Figure 13: Round 3 Section A



Delphi phase

Key findings



Section A, R3: Care environment influences

Section A related to the care environment influences that impact on the person with dementia.

- Panellists were strongly in favour of the person with dementia being central to care planning, with a person centered approach essential.
- The stage and type of dementia should be considered when planning strategies of care.
- Panellists strongly supported the employment of strategies to optimise function.
- Healthcare staff had a role to play in liaising with family members in planning ongoing care strategies however referral to outside agencies was considered outside their remit.

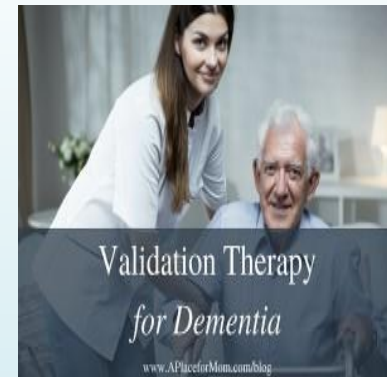
Section B, R3: Therapeutic Lying



Section B related to the use of therapeutic lying as a strategy for use in caring for people with dementia.

- **Panellists were generally in strong agreement that therapeutic lying was acceptable as a strategy particularly if it eased the distress of the person with dementia. It was also useful in reducing challenging behaviours in the person with dementia.**
- **It was important that the person using therapeutic lying knew the person with dementia and had experience of dealing with them.**
- **There was some divergence of opinion on whether the level of dementia impacted on the use of the strategy and a lack of consensus on the use of therapeutic lying to manage treatments.**

Section C, R3: Validation Therapy



Section C related to the use of validation therapy as a strategy for use in caring for people with dementia.

- Panellists were strongly of the opinion that validation therapy promoted communication and interaction with the person with dementia and positively impacted behaviour.
- Panellist choices suggested that they considered validation therapy a more suitable strategy with mild cognitive impairment rather than moderate or severe.

Section D, R3: Reality Orientation Therapy



Section D related to the use of Reality Orientation (RO) therapy as a strategy for use in caring for people with dementia.

- Panellists were strongly of the opinion that RO therapy promoted communication and interaction with the person with dementia and positively impacted behaviour.
- Panellist however were strongly supportive of carers being made aware on the challenges that using RO therapy can entail.

Section E, Round 3: Guidance and information



Section E related to the guidance and information that is important in relation to dementia care and effective strategies that can be used when people with dementia make statements that are false.

Panellists strongly supported the need for education, explicit guidelines and information both for formal and informal carers.

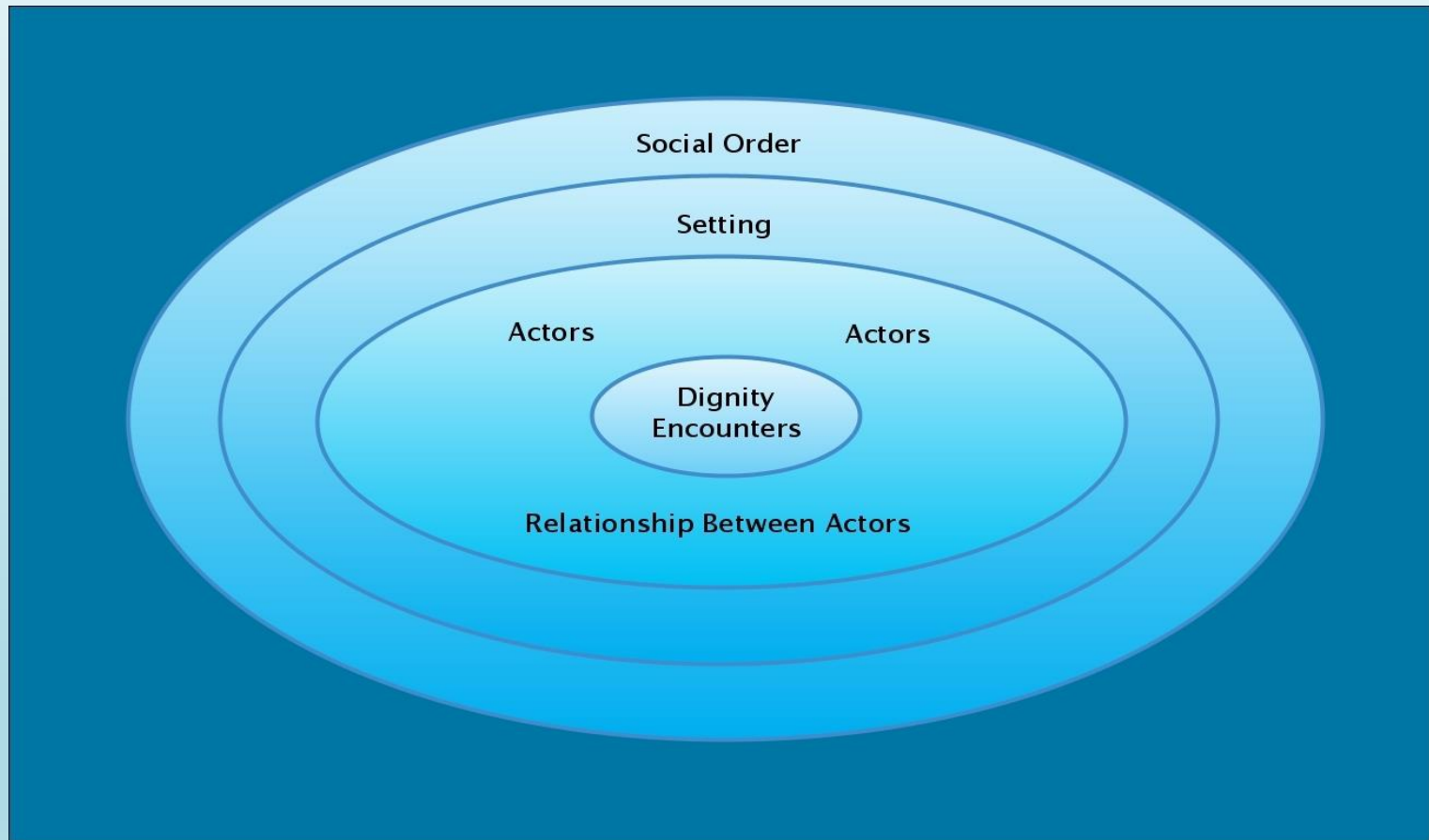


IMPLICATIONS FOR PRACTICE



<ul style="list-style-type: none"> • The person with dementia has to be central to care planning, with a person centred approach essential. 	<ul style="list-style-type: none"> •It is important that the person using therapeutic lying knows the person with dementia and has experience of dealing with them.
<ul style="list-style-type: none"> • It is important to consider the stage and type of dementia when planning strategies of care, and all strategies used should optimise function. 	<ul style="list-style-type: none"> •Validation therapy is useful to promote communication and interaction with the person with dementia and positively impact behaviour.
<ul style="list-style-type: none"> • Healthcare staff having a role to play in liaising with family members in planning ongoing care strategies however referral to outside agencies is outside their remit. 	<p>Validation therapy is a more suitable strategy with mild impairment rather than moderate or severe.</p>
<ul style="list-style-type: none"> • Therapeutic lying is acceptable as a strategy particularly if it eases the distress of the person with dementia. 	<ul style="list-style-type: none"> •RO is an effective therapy particularly in mild dementia: carers need to be made aware of the challenges that using RO therapy can entail.
<ul style="list-style-type: none"> • Therapeutic lying can be useful in reducing challenging behaviours in the person with dementia. 	<ul style="list-style-type: none"> •There is an urgent need for education, explicit guidelines and information both for formal and informal carers.

Dignity



Jacobson (2012)

Recommendations

1. Individualised strategies
2. Optimise functioning's
3. Carers must understand & know
4. Education
5. Lack of clarity/absence guidelines
6. Formal guidelines
7. Review codes of conduct & ethical guidelines
8. Further research larger sample effectiveness
9. Development of spectrum when acceptable therapeutic lying

Principles of Care

Does the approach being used...

1. Avoid harm to the person with dementia?
2. Benefit the person with dementia?
3. Reflect the wishes of the family?
4. Maintain personhood and dignity?

And

1. How will *it* affect me as a person or carer?

Keeping the Voice at the Centre

- ✓ Planning
- ✓ Implementation
- ✓ Final report
- ✓ Dissemination



(Photo courtesy DSDC, Stirling)

Realistically they [people with dementia] are telling the truth, it just happened at a different time in their life.”

(Dementia NI)

Snow Petals

*Gazing out at a garden
Assailed by a sudden hailstorm, you said
“Snowpetals” –
Grasping like a man overboard
For the raft of a word long sunk
In the shifting seas of memory –
“Is that the right word?” you asked
Like a child seeking affirmation.
I smiled, delighting in the endurance
of language, the resistance of the mind
to the closing waters of drowned neurons.
“No” I said “But it’s a better one.”
In the garden the sun-petalled daffodils
Defy the hailstones.*

Carole Farnan, poet & carer



RUROBOTS
Cognitive Science at Work

robosoft
Advanced Robotics Solutions



caretta-net
Innovative IT Services and Systems

R2M
RESEARCH TO MARKET SOLUTION



STOCKPORT
METROPOLITAN BOROUGH COUNCIL



ortelio



MARIO

Managing active and healthy aging with use of caring service robots

Funded by the European Union's Horizon 2020 research and innovation programme, within the thematic section 'Societal Challenge on Health, Demographic Change and Wellbeing'.

MARIO: Managing active and healthy aging with use of caring service robots

- Aims to address the difficult challenges of loneliness, isolation and dementia in older persons through companion/service robots.
- 10 partners from 6 Countries- France, Italy, Greece, Germany, Uk, Ireland
- 3 pilot sites for the introduction of MARIO robot
- Value of Grant: €4million
- Duration 3 years February 2015- February 2018

The Partners

Name	Short Name	Country
Stockport Metropolitan Borough Council	STOCK	United Kingdom
R.U. Robots Limited	RUR	United Kingdom
Universitat PASSAU	PASSAU	Germany
National University of Ireland, Galway	NUIG	Ireland
ROBOSOFT Services Robots	ROBO	France
Ortelio Ltd	ORTELIO	United Kingdom
Fondzione Casa Sollievo Della Sofferenza	IRCCS	Italy
Conisglio Nazionale Delle Ricerche	CNR	Italy
R2M Solution SRL	R2M	Italy
Caretta-Net	CNET	Greece



Why a companion robot?

- 30% of PWD are lonely
- MARIO uses enabling technologies; focuses on:
 - Promoting social connectedness, autonomy
 - Reducing isolation
 - Enhance QOL and slow deterioration



Why MARIO?

- An iPad /smart phone- too complex to access and use.
- iPad disembodied.
- MARIO specifically developed and designed with PWD and carers
- MARIO has
 - An embodied voice
 - easy-to-use interface;
 - a carer/ family can personalise it to individual needs and preferences

The Robot - MARIO Kompai



<http://www.robosoft.com/news/kompai-at-the-2nd-wic-award/index.html>

To find out more go to <http://www.mario-project.eu/portal/>

3 pilot sites

1. Italy – Acute Hospital

- Led by IRCCS Casa Sollievo della Sofferenza
- Acute geriatric department (40 beds)

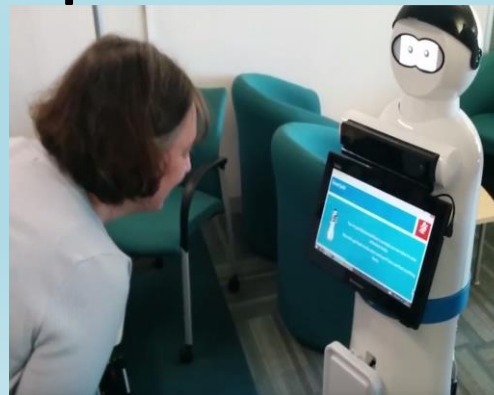


2. Ireland -long-stay residential care

- Led by School of Nursing & Midwifery NUIG
- More than 50% of residents have moderate to severe dementia



3. United Kingdom-Stockport -the community



User Led design

- Identify key requirements that PWD and Carers would like MARIO to have & be able to do, to reduce loneliness and isolation of PWD and enhance connectedness
- What would make MARIO acceptable?



Interviews

- PWD

NUIG=29; Stockport=15; IRCCS=4

Total=48

- Carers

NUIG =49; Stockport=10; IRCCS=20; R2M=13

Total=92

- Relatives: NUIG=7

- **Surveyed:** 130 Carers



I would like Mario to...

- Remind me of daily and weekly events
- Store my phone numbers; important events like birthdays and anniversaries
- Remind me that I had visitors earlier in the day and who they were as sometimes I forget and think no one has visited
- Store and play on demand my favourite music and movies
- Remind me to take my medications, and to eat and drink
- Contact medical help if I fall or am unwell
- Locate my keys or handbag
- Know my favourite book, read it to me; speak loudly so I can hear
- Enable me to contact my family via skype
- Have interactive games; would help me retain my abilities for longer
- Recognise faces so he could prompt me as to who people were
- Know the lay out of my home so he can direct me e.g. to the bathroom
- Speak more like a human
- Will he share my business/secrets with someone else?
- Will he replace the need for a nurse?

So what does this mean for MARIO?

- Prompts the PWD maintaining memory
- Engages PWD in individualised meaningful activities
- Enables PWD to use technology and reduce dependence on others
- Talks to the person; Facilitates & supports choices
- Connects PWD to family & friends
- Personalised activities based on life history
- Has an UI which is simple and intuitive

Stay up-to-date on the MARIO Project

- <https://www.facebook.com/mario.project.eu>
- <https://plus.google.com/116012490277146118083/posts>
- <http://www.mario-project.eu/portal/>
- https://twitter.com/mario_project
- <https://www.youtube.com/channel/UCdxaxbf9BLZjl698HCuTyBQ>
- Paper Casey et al 2016 is available at <https://aran.library.nuigalway.ie/handle/10379/5904>

Promoting Safe Sleep for Infants

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John Devaney⁴ Brid Farrell² Anne Lazenbatt¹ David Hayes¹
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1Queen's University Belfast, Belfast 2Public Health Agency Northern Ireland, Belfast 3Southern Health & Social Care Trust 4South Eastern Health & Social Care Trust 5Safeguarding Board for Northern Ireland

Background

- Over the past 30 years the infant death rate has more than halved in Northern Ireland, falling from 10.5 infant deaths per 1,000 live births in 1984 to 5.1 in 2015
- During the calendar years 2013-2015 inclusive, there were 15 deaths of infants in Northern Ireland due to Sudden Infant Death Syndrome (SIDS)
- Some of these deaths occurred in families where there were current or previous concerns about the care of children
- A number of notifications made to the Safeguarding Board for Northern Ireland for consideration of the need for case management reviews



What is SIDS?

Sudden Infant Death Syndrome (SIDS) is defined as the sudden and unexpected death of an infant under 1 year of age, with the onset of the lethal episode apparently occurring during sleep that remains unexplained after a thorough investigation including performance of a complete autopsy, and a review of the circumstances of death.

There has been a gradual change in the profile of such deaths over the last twenty years.

What is co-sleeping?

Co-sleeping is defined as the situation where an adult (usually the infant's mother or father, or both; or sibling/s) brings an infant onto the same sleeping surface (usually a bed or sofa but not limited to these surfaces e.g. couch, futon, armchair, water bed, beanbag chair) when co-sleeping is possible, whether the intention is to sleep or not.

Triple Risk Model

A vulnerable infant

A critical development period for the child

An exogenous stressor

Research Study

- Partnership approach
- Funding from the Public Health Agency NI and the Safeguarding Board for Northern Ireland
- Research strands:
 - a scoping review of the international literature on co-sleeping and infant death
 - a retrospective review of deaths of infants of relevant causes (aged 0-2 years) (n=45)
 - qualitative research involving interviews

Summary of Research Literature

- Co-sleeping varies by culture and country and is known to be a common practice in the UK
- While deaths through co-sleeping are less common in the first month of life, they peak between 2 and 4 months, and approximately 90 per cent occur by 6 months
- There is an increase in the numbers of deaths during the winter months, with the reasons for this previously theorized to be related to increased viral illnesses at this time or overheating due to carers over-bundling the infant
- Evidence shows an increased risk of SIDS among infants who are sharing sleep surfaces especially in the presence of other factors
- There are limitations in the evidence of the inter-relationships with factors such as breastfeeding

Case Review Methodology

A retrospective review of all paediatric deaths of infants (aged 0-2 years) referred to the Coroner's Office for Northern Ireland between January 2007 and December 2013 where the death was certified as SUDI / Unascertained / Wedging / SIDS / Co-Sleeping / Overlaying or any combination of these causes (n=45)

Results (Demographics)

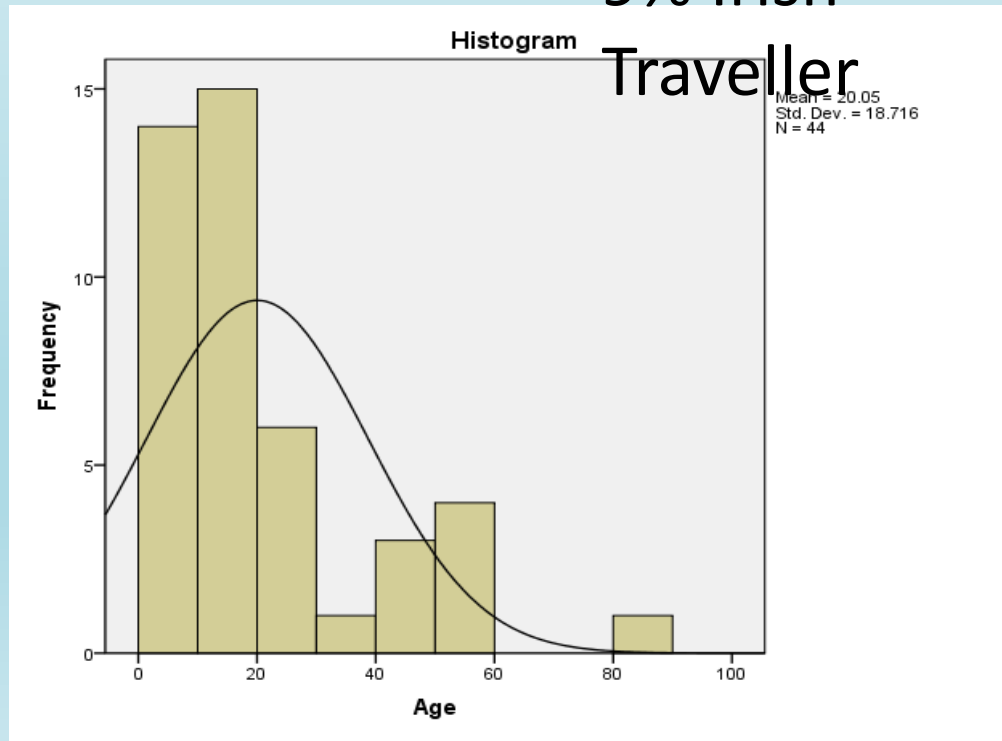
Sex

- 33.33% Female
- 66.67% Male

Ethnicity

- 91% white ethnicity
- 9% Irish

Age



Results (Circumstances of death)

- 71.1% deaths associated with co-sleeping (n=45)
- 56% died in their parent's bedroom, 20% in the living room and 2% in a car seat (n=45)
- In 2% cases were covers found over the child's head (n=45)
- 16% cases the child was away from home (n=45)
- 24% cases it was a family occasion (n=45)
- 52% cases alcohol was taken by caregivers (n=44)
- 59% cases who were co-sleeping the co-sleeper had taken alcohol (n=32)

Focus Groups with Professionals

- In interviews with midwives, health visitors and paediatricians for this study there was widespread recognition of safe sleep messages, although also some concern about competing advice that may not be consistent, ranging from never sleeping with your baby to promotion of bed sharing in the context of breastfeeding.
- Practitioners often reported co-sleeping with their own baby.
- Advice given to mothers, rather than including fathers and other adult carers
- Need for non-judgemental and consistent advice

Current Best Advice



For parents



For professionals

Next Steps

- Briefing paper for professionals
- Public Health Agency NI SIDS Risk Assessment Tool
- Awareness raising among both health and social care professionals

