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Slide Presentation: So what have the romans researchers ever done for us - MARIO

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So what have the ~~Romans~~ Researchers
ever done for us?

**Monty Python:
Life of Brian**



**Professor Dympna Casey
School of Nursing & Midwifery
NUI Galway**



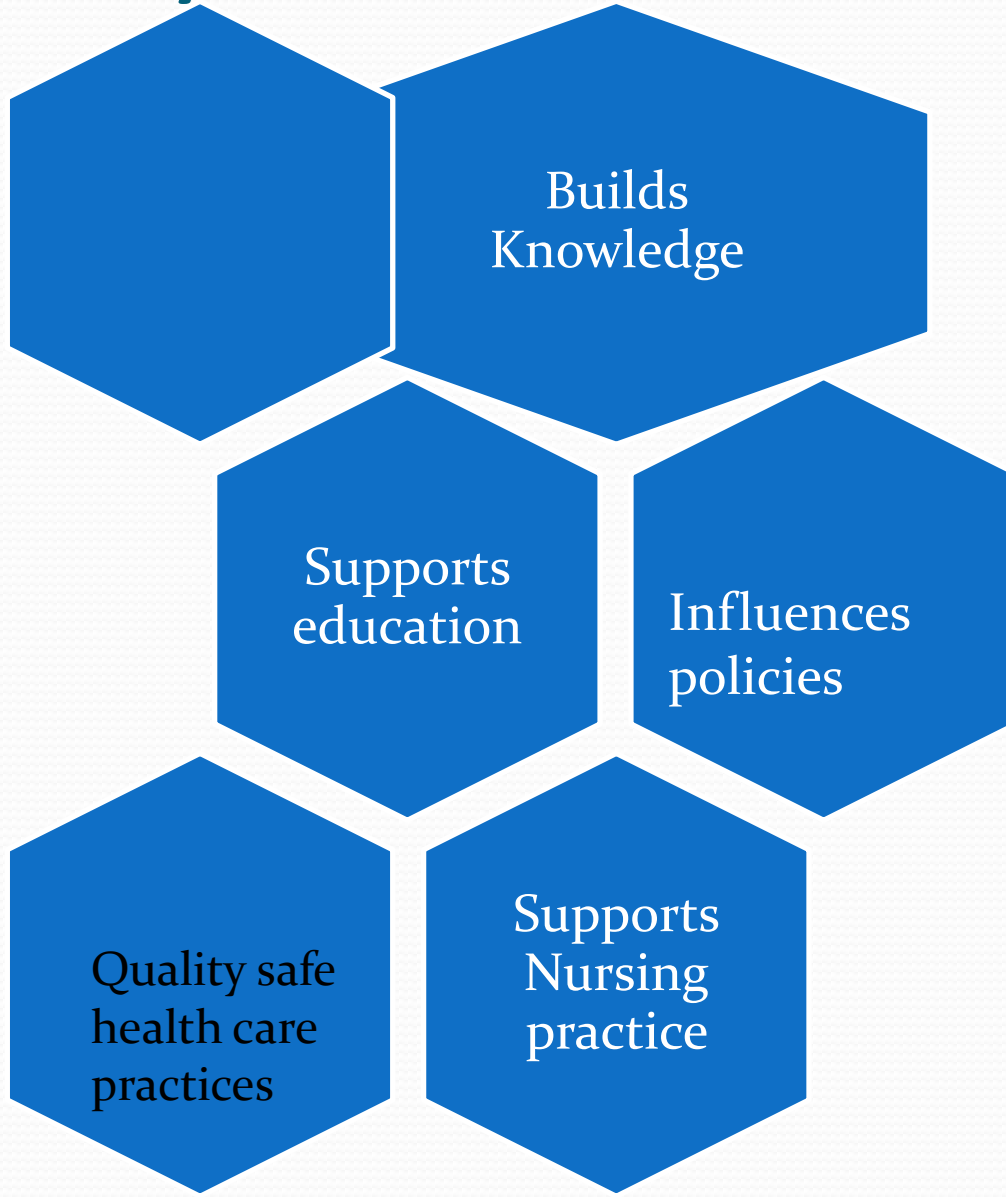
Focus of this presentation

- What is research and why research matters?
- Talk to you about dementia and share with you some of the studies I have been involved with, and how these studies seek to promote social health and **why they matter!**
- **DARES** and reminiscence,
- **Resilience** -its importance for people with dementia and how we need to maintain and build social connectedness and social networks
- **MARIO** which seeks to enhance social connectedness, reduce loneliness and isolation through the use of companion robots

What is research?

Discovery Alteration
Inspiration Creativity
Technology Experiment
Idea Change
Innovation
Research Improvement
Development Analysis
Concept Invention
Decision Prototype Science

Why research matters!



**Makes a real
difference to
patients lives.**

Some Dementia stats...



- 44.35 million people have dementia and expected to reach 135.46 million by 2050 (Alzheimer's Disease International 2013).
- Western Europe has the highest prevalence of dementia in the world (Ferri et al. 2005; Prince 2009)
 - 7 million in 2013 (Alcove 2013) and a projected increase to 13.4 million by 2050 (Prince 2009).
- It is estimated that one new case of dementia is added every three seconds (Prince 2015)

Some Irish stats...



Total number of people with dementia	Number of people >65 with dementia	PWD living in the community	PWD living in long stay residential settings/nursing homes
41,470	37,887	26,104	14,266

Living with dementia

- (3.16 minutes)

Dementia research studies

- Now going to look at some of the studies I have been involved with in relation to Dementia, and how these sought and seek to make a difference and promote social health
- 1. DARES promoting quality of life and social health through reminiscence,



Dementia Education Programme Incorporating Reminiscence for Staff (DARES)

Key questions

- Can a structured education reminiscence-based programme make an ongoing difference to day-to-day care?
- Will using reminiscence make a difference to residents with dementia?

What we did

- Cluster randomised trial, with an embedded qualitative component
- Sample Size
 - 18 long-stay units
 - 17 residents with dementia per unit
 - 10 staff per unit
 - Total 304 residents and 180 staff



Phases of Dares

Phase One

Developed structured education programme, pilot of intervention one site

Qualitative interviews, experts, people with dementia, understand

Concept Analysis understanding reminiscence

Phase two

Phase 2
RCT
Cluster randomized trial

,Qualitative interviews, experience of DARES intervention

Qualitative interviews, to illuminate usual care

153 residents with dementia intervention

151 residents with dementia control

Reminiscence

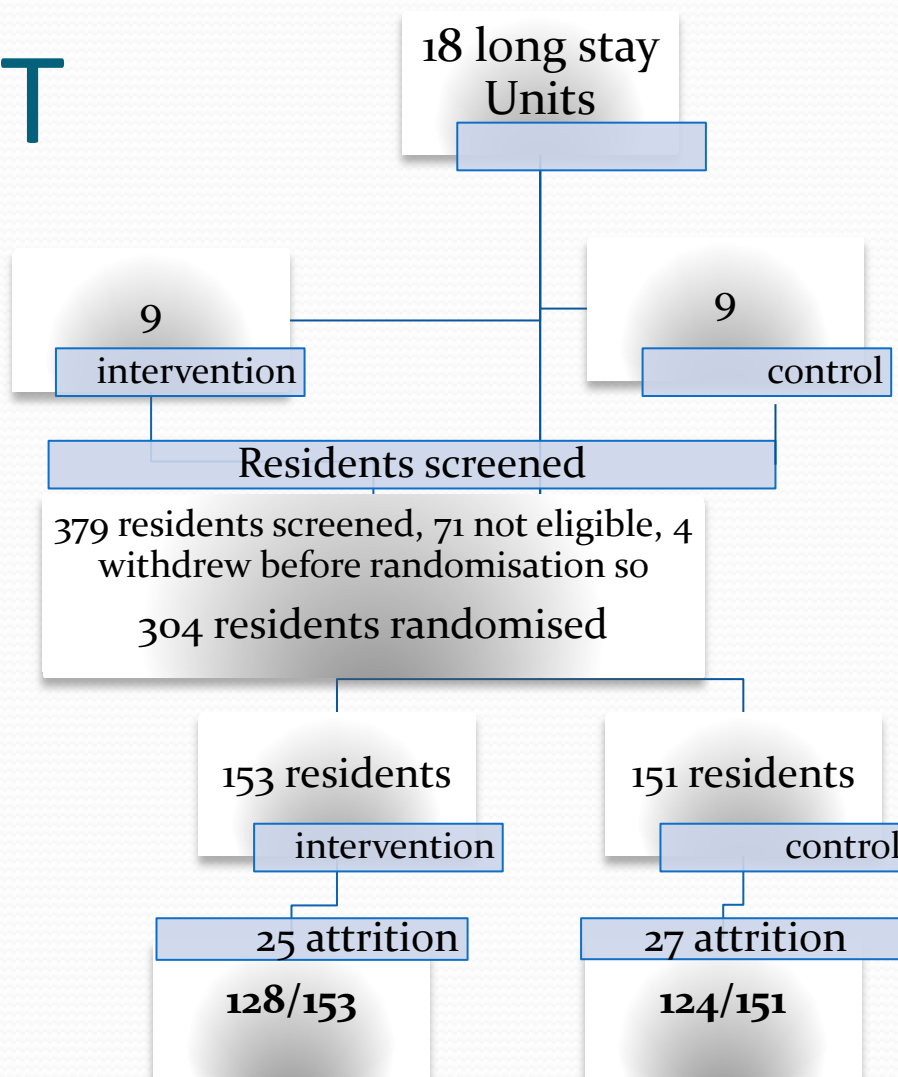
- Reminiscence focuses on supporting people to think or talk about past events, experiences or activities (Woods *et al.* 2005, Cotelli *et al.* 2012).
- Reminiscence works with early memories that are preserved into late stages of dementia and enables the person with dementia to communicate and interact with the listener in the present (Subramaniam *et al.* 2012 Gibson 2011, Woods *et al.* 2005).
- Reminiscence involves the use of prompts to the senses to facilitate the recall of memories from the past



Process

- The structured programme for staff delivered in 9 intervention sites; the DARES team ran the programme for 10 staff in each site, it was a 3 day programme.
- Formed 5 dyads of staff nurse and health care assistant who worked with 3-4 residents with dementia. Over the intervention period life histories of residents compiled and the knowledge gained used to give one formal and two information sessions of reminiscence with each resident guided by their interests
- Sites audited by DARES team to monitor the fidelity of intervention, records kept of reminiscence sessions and discussed with staff participants
- Three sites failed to implement the reminiscence with residents, staff turnover, roster changes cited as the issue.

DARES RCT



Demographics



Intervention (N=153)

Control (N=151)

Age in years		
Mean (standard deviation)	85.2 (7.1)	85.7 (7.1)
Sex		
Females - number (%)	110 (72)	99 (66)
Males – number (%)	43 (28)	52 (34)
Mini Mental State Examination score (MMSE)		
Mean (standard deviation)	12.98 (5.5)	11.70 (5.4)

What we measured and found

- **Primary outcome measure:** QOL-AD for quality of life
- **Secondary outcomes:**
 - Cohen Mansfield Agitation Inventory (CMAI); Cornell Scale for Depression in Dementia; The Modified-Nursing Assessment Care Scale (M-NCAS) for carer burden
- ITT- Slight improvement in the QoL-AD resident score for the intervention group at follow-up period
- The magnitude of change was not significant

Per Protocol Analysis

- If the data from the three sites that did not implement the intervention were removed the change is significant
- A clinically and statistically significant effect of the intervention on the QoL of residents, with those in the intervention group experiencing a 5.22 point improvement in quality of life, compared with those in the control group ($p = 0.04$, 95% CI 0.11, 10.34).

Effect estimates: intention to treat (ITT) and per protocol (PP) analysis

	ITT Estimated effect (95% confidence interval (CI))	PP Estimated effect (95% confidence interval (CI))
QoL-AD resident score	3.54*** (-0.83, 7.90)	5.22* (0.11, 10.34)
QoL-AD caregiver score	1.14 (-0.35, 3.62)	1.40 (-1.75, 4.55)
CMAI score	-3.35 (-8.10, 1.82)	-2.14 (-7.94, 3.67)
CSDD score	-1.33** (-3.04, -0.36)	-0.86 (-2.66, 0.93)
MZBI score – nurse	0.97 (-1.13, 3.08)	1.50 (-0.73, 3.74)
MZBI score –care assistant	0.42 (-1.82, 2.67)	0.86 (-1.22, 2.94)



But what was it like for the
participants and end users?

Embedded Grounded theory study

- Designed to capture the impact of the Structured Education Programme on participants
- Focused on four sites (Public n = 2, Private n = 2).
- Data was collected using in-depth interviews

People with dementia: demographics

- PwD (n=11)
- Ages range 70-96 yrs
- Majority female (n=10)
- Length of stay ranged 3 months- 6 years
- MMSE mean score of 14,9- most moderate dementia



Staff Demographics

- Staff (n=22)
- RGN (n=9); HCA n=10; Managers (n=3)
- Most RGN's and HCA 50+ ; Manager in 40's age group
- Most RGN's and HCA's worked 1-10 years with older people



Findings: “Seeing me (through my memories)”



- Through reminiscing, learning the stories of PWD, listening to their memories, the person (me) was revealed to staff in unexpected ways.
- Staff also perceived that the PWD saw them as individuals and engaged with them differently than before.
- Knowing who the person was (their past) helped to understand what mattered to them (in the present) and helped staff to relate to and connect to the person (and vice versa) in new ways.

“(The staff ask) ‘did you go dancing?’ ... I would be laughing away and I’d be telling them this. I’d say to them ‘what in God’s name am I after doing boring the hell out of (you)’ but I used to feel good then ... I feel happy ...” (Resident P342))

“(Bit by bit we built up her life story and I was surprised) by her sense of devilment ... her character when she was growing up ... you don’t see that when somebody is eighty-something, but the stories she used to be telling me, I enjoyed it. I was enjoying it with her and she was as well. It was good ... they come alive when they’re talking about it.” (Nurse 194)

I think they (Staff) (know my father) now because I have spoken to them and the fact that this (DARES) is going on as well is a real help. I think it’s a great help to give them a better insight into what his interests were before he went into them and what he liked. (Relative 02)

1. Seeing & Knowing the Person



“I got to know them (PWD) all really, really well ... and our relationship was much, much stronger and I could get through to [Name] ... She used to fight an awful lot with this other client ... I could get through to her an awful lot quicker because we had that special bond because we had sat and talked about her loved ones.”
(Nurse 013)

“I bring in my (family) photographs ... Plenty of them and they were very interested

INT: And what then? So, what kind of pictures, what would you be showing them pictures of?

Of my children. How they grew up and how they emigrated and got employment and all that and worked for a living ... I think they're interested. They're interested to know.” (Resident P034)

2. Reminiscence “... a key”

Unlocked the person's past and enabled staff to engage in a different way and vice versa.



“We were buttering bread and his mum used to make butter, so we were talking about how he used to make the butter and milking the cows ... I suppose it makes me feel that I’m connecting with him on a level he remembers, that is specific to him. That it’s not just general chit-chat ... but it’s actually important to him because it’s something he can relate to ...” (Nurse 192)

Int: What's the thing that you most enjoy talking about?

When we talk about farming and what work you had to do and things like that.” (Resident P041)

3. Understanding & Accommodating

“He used to just wander the corridors and it was only afterwards when we started doing this (reminiscence) that we asked him and he was putting sheep in the pen ... He used to take all the fire extinguishers and he'd put them all in the corner and we said, ‘what in God's name ...’ but he was actually making a pen for the sheep and this was what he was doing ...

And was that something that perhaps you tried to stop him doing before?

Yeah, you'd be saying for ‘God's sake,’ would you ever nail them on? Whereas now, I find, I let him do it.” (HCA 011)

“... one of my residents (has a) very, very erratic personality and very hard to calm down when she's irate. I've noticed a huge difference in her when you speak to her and you tell her things she wants to hear, she gets wrapped up in this conversation and it really helps...(reminiscence) calms her down unbelievably so, when you speak about something that's familiar to her ... and she sees actually I know her and that is a big thing for her. ... (I have learnt) she's not just a confused resident. She has had a life.”” (Nurse 174)

Findings Summary

- Staff surprised at the capacity of PWD to communicate and interact.
- Reminiscing helped staff to better understand and appreciate the person beyond the dementia.
- Opportunity to fundamentally change the lives of PWD.



So what has this research given us

- Demonstrates that Reminiscence has a positive effect on quality of life, over an 18–22 week period, significantly so when examined on a per-protocol basis.
- Qualitative work identified how important getting to know the resident was, how important knowing about dementia was.
- Reminiscence **makes a real difference** in clinical practice and to the lives of people with dementia and their families
- Rolled out the programme to the controls; use the material to inform our teaching degree and PG dip in gerontology; findings contribute to systematic reviews on reminiscence so adding to the evidence base that Reminiscence makes a difference!

2. Resilience

- Now I want to share with you our work on Resilience and its importance for people with dementia and how social connectedness and social networks are an important element of resilience building

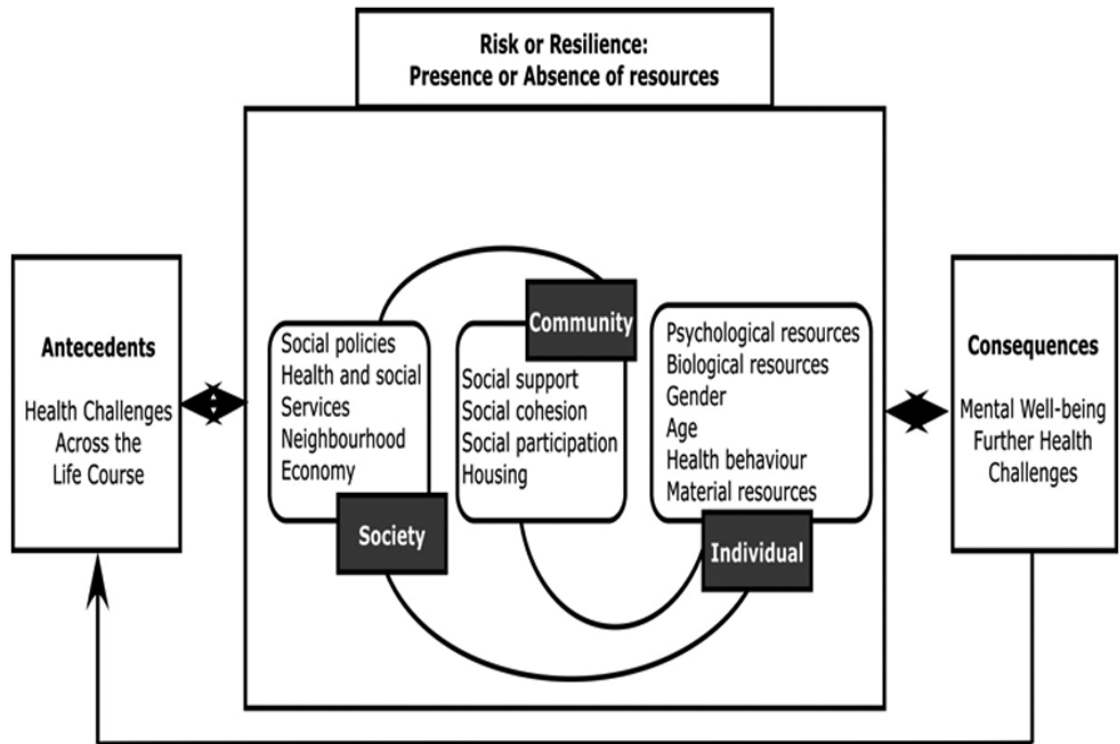


What is Resilience and why its important in dementia

- Resilience refers to one's ability to 'bounce back' and cope in the face of adversity.
- Participation of people with dementia in family and civic life is diminished by cultures of exclusion and stigmatization.
- Building resilience has been identified as a strategy that may help foster social inclusion, social connectedness of people with dementia prevent isolation and promote social health
- However despite the recognized potential of resilience theory, the extent to which resilience exists or can be cultivated and nurtured in people with dementia is still relatively unknown.

Resilience Framework (Windle 2011)

- Windle (2011) defines resilience as ‘the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma.
- ‘behavioural process’ built on strengthening personal attributes and external assets such as supportive relationships and community resources
- to increase the person’s ‘hardiness’ to remain psychologically and physically healthy (resilient) in the face of adversity.



Resilience and People with Dementia

Aim: to explore people with dementias' perceptions of resilience and the factors that facilitated or hindered their capacity to develop resilience.

Methods:

- A descriptive qualitative study
- 1:1 interviews with 6 people with mild to moderate dementia living in the community in Ireland.
- The CORTE interviewing framework (Murphy et al 2014) was used to guide the interview process; consists of four main areas; gaining COnsent, maximizing Responses, Telling the story, and Ending on a high. This process maximizes the meaningful involvement
- All interviews were tape recorded and transcribed verbatim.
- Transcripts were analyzed for themes using the constant comparative technique and Windle (2012) resilience framework was used to guide the analysis.
- The criteria identified by Lincoln and Guba (1985) were used to ensure and maintain rigor. Ethical Approval was obtained from NUI Galway.

Demographics

Participants	Gender	Age Range	No. Years with memory loss	Highest level of education
o2o914	Female	60-69	1-3	Second Level
WS320069	Female	60-69	1-3	RGN/RGM
o1o914	Female	60-69	1-3	Degree
o8o414	Female	70-79	4-6	Technical Vocational
o4o414	Male	70-79	4-6	Second Level
WS320070	Male	70-79	1-3	Masters

Findings :Perceptions of resilience

Most participants felt that resilience had to do with :

When it was fully explained that resilience was about 'bouncing back' in the face of their memory loss, most felt that they were resilient to some extent

It's, kind of, coping, is it, yea, with, with my lifestyle, I suppose, really and, and the memory loss as such. (080414)

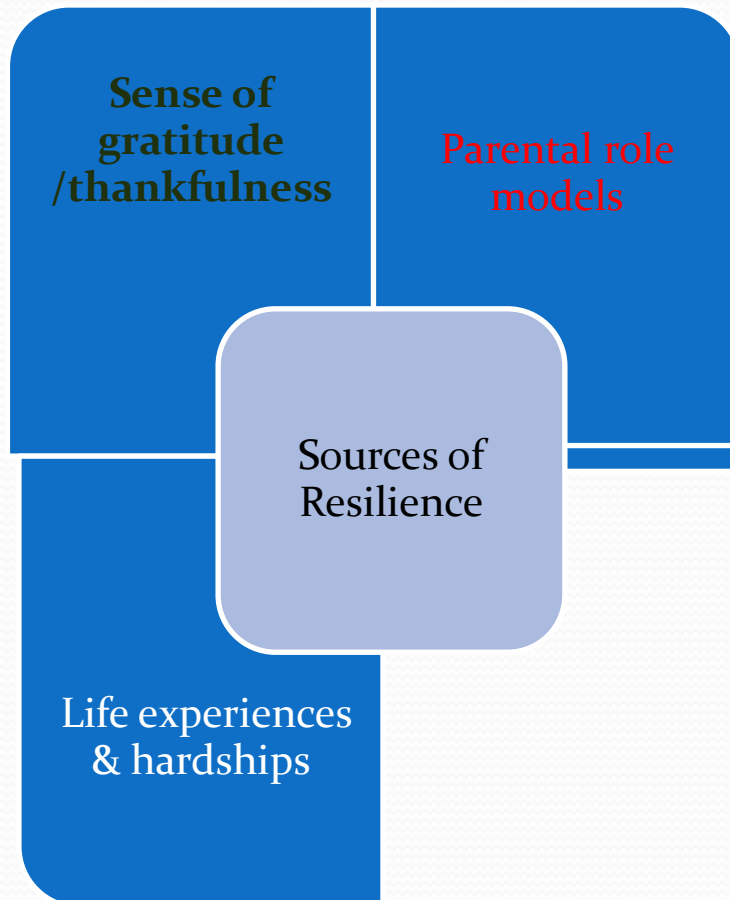
"...for me anyway, is that you continue to fight..." (040414)

"That you can remember things, is it, I don't know." (020914)

"I'd say I have a bit of, you know, that (*resilience*) in me alright. I'd say that I wouldn't be put down very easily". (WS320069)

If I'm partially honest, if I'm fully honest – partially I am and partially I'm not, (010914)

Sources of resilience



Ah yea, well see we've been lucky enough. We've been able to, to travel the world...great friends over them years...and had a great time...You know, great memories, like, you know., Well, what I remember. (o8o414)

Mom was a social worker through the Blitz in Manchester. And she had to leave home at 14, because her mum had died, and she had to go working, to make money, and then go to England to support her sister....And I always think of what she has gone through, and what she has done, you know...It gives me the strength (o1o914)

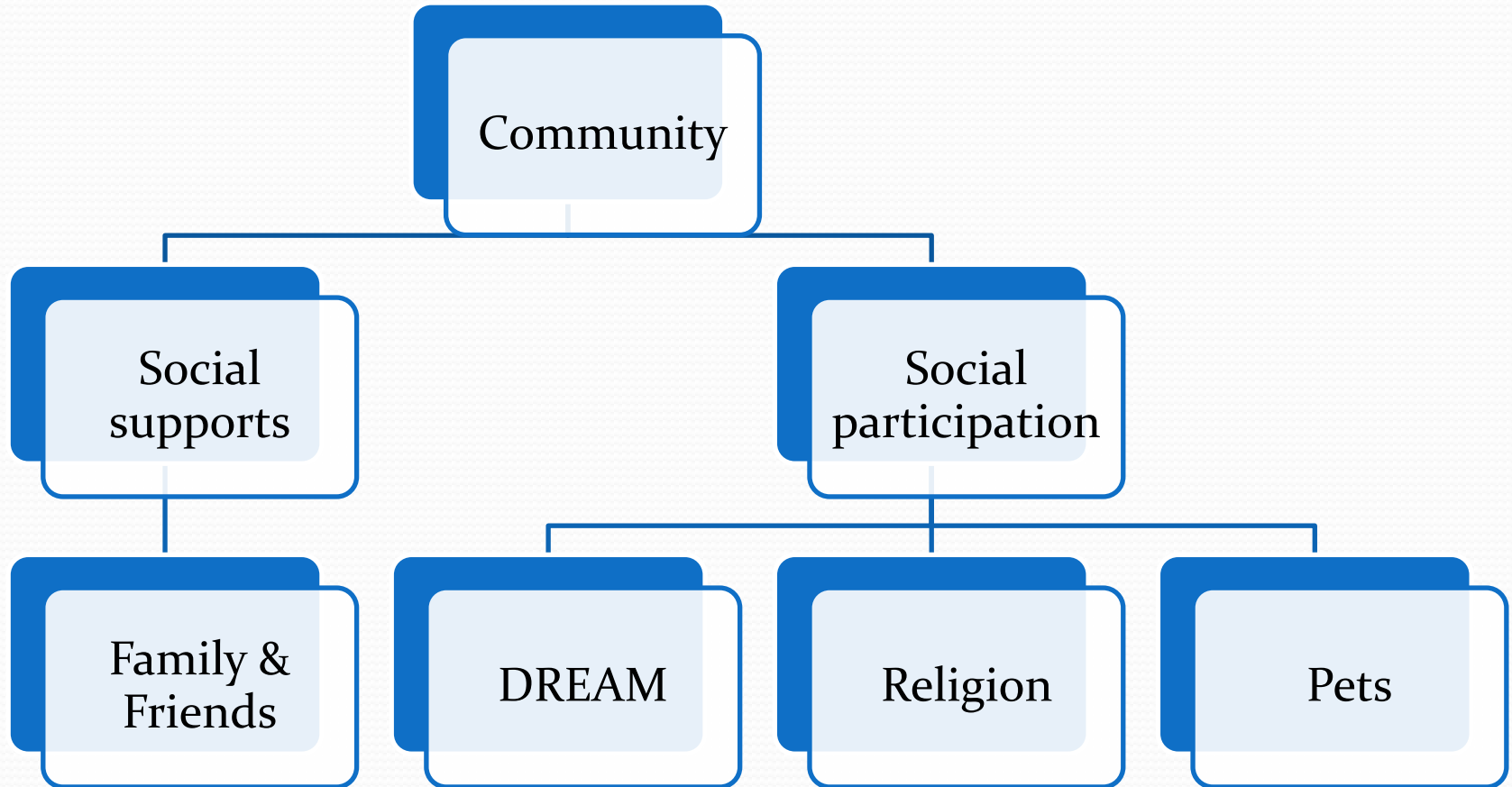
Where did you get that spirit from?

From... I'd say it was family kind of. Do you know?... I worked in Dublin first of all, I trained there as a nurse....Seventeen when I left home, that's right..

Carer: : And there were times you didn't come home for nine months. You know, it's like you were in America.

Yeah, nine months, you'd be a year before you get your holidays....the way it went, you know? It never bothered me, like, you know, I just took it and went with it and that was it, you know? (WS3200069)

Factors that facilitate resilience



SOCIAL SUPPORTS –FAMILY AND FRIENDS

And how did you manage to go back (*playing cards*) ? What happened that made you go back?

My friend made me

Q She knew (*about the memory problems*) , and she made you?

Yea, yea, yea she was the first person, I lived next door to her on xxx Road when we came here thirty-six years ago, and when her children were young I used to often help, and we are best buddies, best best buddies

Q So that support that you got from her was crucial for you to go back and play the games?

yeah

(010914)

there's four sisters...And we meet up every Wednesday afternoon.

Q:Every Wednesday?

A:Yea with...

Q:And where do you meet?

Here or in their houses, you know, we, kind of, go around.

Husband: Different houses, they go around...

Q: Okay, so that's, that's something you look forward to?

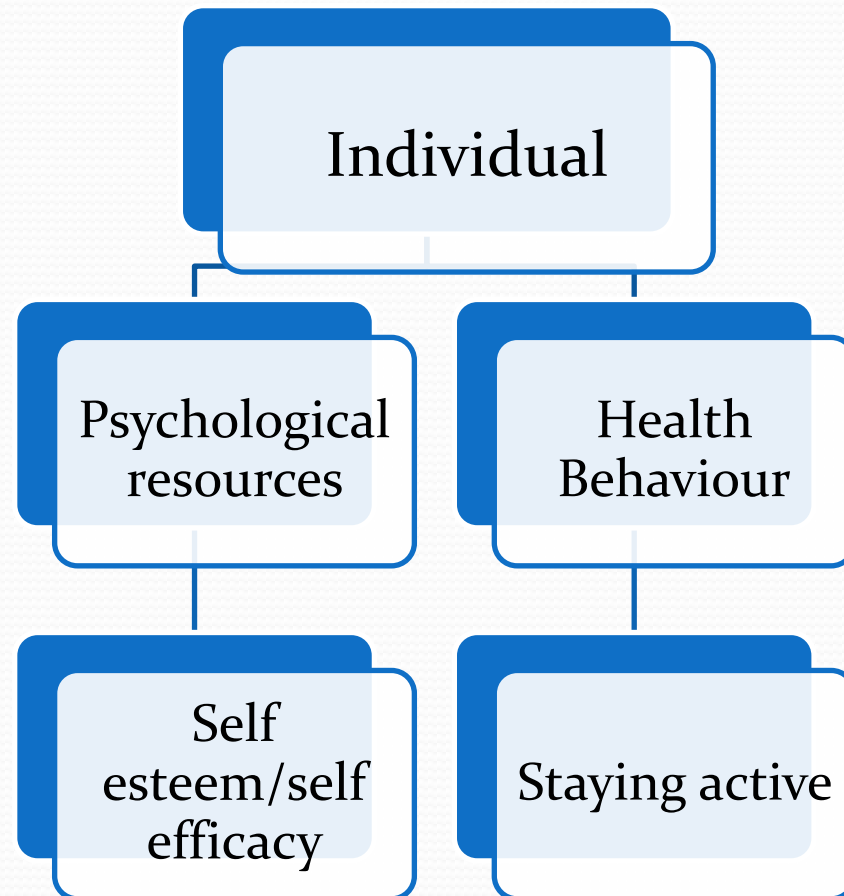
Oh Lord, yes, yea, yea.
(080414)

Having a pet

And it probably sounds silly, but that dog paves the way for a lot of things for me. Having a pet, it helps you...I feel sorry for her, she hasn't been down to see any dogs, she's a very friendly girl, so I take her to xxx beach and she knows the nice ones!...And they go to her. And the people then will speak to me. And it's called the "Dog Romp" you know, so I go down there, I know I'll see somebody, I don't know them, but I know their dog, and likewise...So I'm looking after her, so she is my focus, when I leave the house she is my focus, and there is interaction with people that I never thought...yea there is interaction with people that know me, as me, not as what I was...

(010914)

Factors that facilitate resilience



Self efficacy

Being positive; having a sense of humour; a sense of purpose; fighting spirit

Well, generally, I do try to have a positive attitude because I know that if I. If I think negatively about something, I'll say, well right, that's going down the wrong road, you know. And I do try to think positive and himself, as I said, is great support. To think positive, you know. So I, I do feel, definitely, thinking positive, yes. (080414)

...I think it is, I think it's important, yeah, I mean you have to have something that's going to interest you from day to day, whether it's, and in any part of your life, you really need something, but yeah, it is yeah, important form e to have things to do (WS320070)

And do you believe in persevering with things x
I do.

So you've a fighting spirit have you.

Yes.

Q Have you always been that kind of a person.

I have, but this is the worst thing ever. (020914)

Factors that hinder resilience

Individual

Psychological
resources

Personal
competence
& Control

What's the most difficult part for you xx?

See the thing about work, that gets you out...

And you work, you do something productive?

You do, you can.

And that's the worst part of having...your problems with your memory now, is that you can't do that?

I can't do it, no. I, it seems that I can't but I want to. I, I, I, I'm a broken human being, you know. (040414)

No, now I used to read a lot, like, and I enjoyed reading but I'd given up on the reading. If I could get that back again I'd be very happy. (WS320069)

Doing the baking, actively doing something, cooking the dinner...

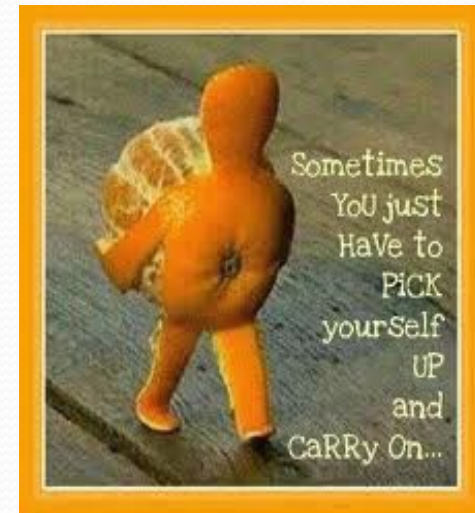
Ah no I'm not able for that anymore.

Q You're not able for that...

Husband: they (the children) wouldn't expect her. Ah they wouldn't, in fairness, they'd be bringing us out ...(020914)

So what has this research told us

- Most people with dementia understood resilience and feel they can be resilient
- Learning from life experiences, parents as role models and a sense of gratitude seem to be important resources for resilience
- Foundations for building capacity for resilience at
 - Community level includes social supports and social participation, relationships matter
 - Individual level- self confidence, belief in self, staying positive, having a sense of humor, and a fighting spirit and staying active
- Most feel they have the capacity to be resilient and building resilience matters.



3. MARIO

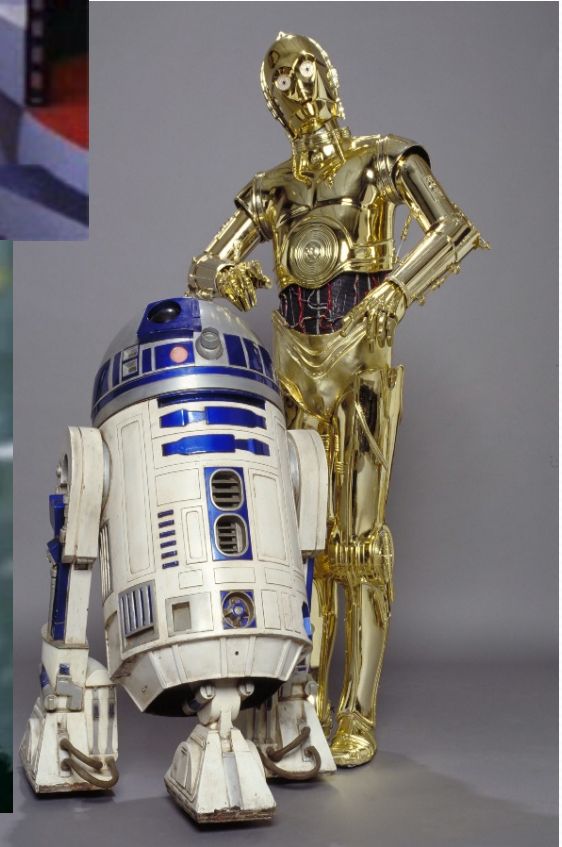
- The final study I want to share with you which I am leading and is currently underway is the EU Horizon 2020 funded study called MARIO.



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 –
 - Italy (Acute Hospital) , UK (Community) & Ireland (Nursing Homes)
- Value of Grant: €4million
- Lead by NUIG
- Duration 3 years February 2015- February 2018





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/>

"Technology is nothing. What's important is that you have a faith in people, that they're basically good and smart, and if you give them tools, they'll do wonderful things with them."

:- Steve Jobs



Perceptions of people with dementia and carers on robot companions (MARIO)

- The work has focused on developing the functionalities for MARIO and a key part of this work involves finding out what the users ie people with dementia , caregivers and families felt about having a robot companion and what they would like this robot to have
- Today I want to share with you what participants in the Irish pilot sites told us



Methodology

- Three focus group interviews with people with mild/moderate dementia.
- 2 Focus groups with health care staff in nursing homes
- Qualitative content analysis was used to analyze the data
- Criteria identified by Lincoln and Guba (1985) was used to ensure and maintain rigor
- Ethical approval obtained

Demographics of People with dementia

- Nursing Home A (n=8)
- Female (n=5) Male (n=3) Majority > 80 Year (n=7)
- Nursing Home B (n=5)
- Male (n= 5) Majority >80 yrs (n=4)
- Community (n=9)
- Male (n=5) Female (n=4) All > 65 yrs

Findings

- The majority of participants were receptive to the idea of having the robot companion Mario Kompai


“It would be nice to have it alright...Oh yes sure it would be, I’d be all into it “(FGB)

What I would like Mario Kompai to do for me

- Recognise peoples individual voices and remind me of daily and weekly events;
- Store my phone numbers and important events like birthdays and anniversaries;
- 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;
- Know the lay out of my home so he can direct me e.g. to the bathroom;

- Locate my keys or handbag
- Know my favourite book and read it to me
- Have interactive games that I would enjoy and would help me retain my abilities for longer
- Recognise faces so he could prompt me as to who people were.
- Interact with and regulate other technologies in my home

"Maybe putting on a television... You want the channel or something. This yoke is, how do I get the channel, you know, it's not easy... but if you had something that would say ok just give me a tip again about how to get BBC6 if there was such a thing... Because some of these remotes are so complicated, you'd want to be in the full of your health to follow them, I have to say".
(FGC)

- 
- Motivate me and deliver words of encouragement when I'm less inclined to do something e.g. 'lets do it' "Don't give up" " come on have a go" .
 - Play soothing music to me at night and to gently wake me in the morning
 - Remind me that I had visitors earlier in the day and who they were as sometimes I forget and think no one has visited?

Appearance

- Speak more like a human
- The voice needs to be clear, he needs to speak slowly and a bit loudly so we can hear
- To have more softer or warm features, soft to touch 'he is like a fridge'
- Could he have some hair? Can we put some clothes on him to make him a bit more friendly in appearance?
- Can he appreciate humour and 'have a laugh' with us.



Concerns

- He needs to be robust, what if we accidentally knock into him or maybe we could even fall over him?
- Where will he hold all his information, on a 'chip in his head? '
- Will 'my secretes' be safe with MARIO?
- Who will have access to the information that I give to MARIO?
- Will he share my business /secrets with someone else?

Staying Connected



- Most participants recognized the potential of Mario Kompai to keep them connected to family and friends
- Wanted him to have skype and thereby connect them to their friends and family

“...I could talk to my girls on skype” (FGA)

- Wanted him to have access to their life history/life story, their interests and hobbies and could use this information to foster conversations and reminisce about events that they could remember more easily.

- It is clear that that Mario Kompai has to really get to know the person and their daily routines

“...{Its} building in the person's routine so it's like you're getting up, you've got to go to the toilet, you've got to brush your teeth, you're going to have your breakfast now so it's the routines as well as the memories but the routines I think are important...”(FGC)

Demographics of health professionals

- Nursing Home A (n=23)
- Female (n=20) Male (n=2) 1 did not answer
- Majority (n= 17) >40 yrs.
- 13 RGN's 6 HCA 2 Activity Cord. 1 Physio. 1 OT.

- Nursing Home B (n=26)
- Male (n=4) Female (n=21) 1 did not answer
- Majority (n=18) >40 yrs.
- 15 RGN's 7 HCA 1 Activity Cord. 1 Physi
2 OT.



What we would like in Mario Kompai

- All welcomed the idea of MARIO and were keen to meet him in person!
- Have MARIO undertake some of the **Comprehensive Geriatric Assessment**,
- Have a falls detection sensor; Sensors to pick up the residents physiological status;
- Voice activation and face recognition
- Ability to skype ; take photos of the resident to share with family members
- Record visitors names and details when they visit?
- Orientate residents to time place and date



- Must have the persons life story
- Be able to read the local parish newsletters, show local football games on his TV screen; the horse racing etc.
- Identify someone in distress in terms of their emotional wellbeing
- Could he smile, express some emotion, appear to make eye contact
- Needs to speak like a human not a computer
- Maybe give him a wig and put clothes on him, make him more friendly



Concerns

- Space
- Privacy and confidentiality of the information stored in MARIO.
- Needs to be robust as they could hit him and knock him over
- Who will be responsible for MARIO? , what if his system crashes while he is here, how does he reboot?
- **Will MARIO replace the need for a nurse ?**



What Next in the MARIO project?

- **Translating the wish list into reality**
- Finalising the functionalities and architecture for Mario Kompai



Stay up-to-date on the MARIO Project at:

- <https://www.facebook.com/mario.project.eu>
- <http://www.mario-project.eu/portal/>
- https://twitter.com/mario_project



Conclusion: So what has this research done for us?

**Monty Python:
Life of Brian**



Tells us that: we can make a difference!

- Reminiscence can make a difference to people with dementia and to caregivers;
- Resilience is important for PWD and social connectedness is a key element of resilience building
- Companion robots appear to be acceptable to people with dementia and to caregivers and they believe they have the potential to promote social connectedness
- Person-centred care must underpin good practice; and the importance of knowing the person is key.
- People with dementia can tell us what they want
- We just must take the time to **ask and listen**

Researchers and the evidence we generate can make a real difference to our practice and to our patients/clients lives!