



IPA INTERNATIONAL PSYCHOGERIATRIC ASSOCIATION

International Congress

13-16 October 2015

Balancing Cure with Care: Advances in Late Life Mental Health

The research leading to these results has received funding from the European Union Horizons 2020 – the Framework Programme for Research and Innovation (2014-2020) under grant agreement 643808 Project MARIO 'Managing active and healthy aging with use of caring service robots.'

THE PERCEPTIONS OF PEOPLE WITH DEMENTIA ON THE FACTORS THAT STRENGTHEN THEIR RESILIENCE.

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“I’d say I have a bit of, you know, that (resilience) in me alright”

“Granted, the Board of Directors didn’t think much of your proposal, but I think they’ll be impressed by your resilience!”



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BACKGROUND AND WHY IMPORTANT

- 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 of people with dementia within communities.
- Resilience refers to one's ability to 'bounce back' and cope in the face of adversity.
- 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. **Dementia is seen by some as negating the ability to develop resilience.**

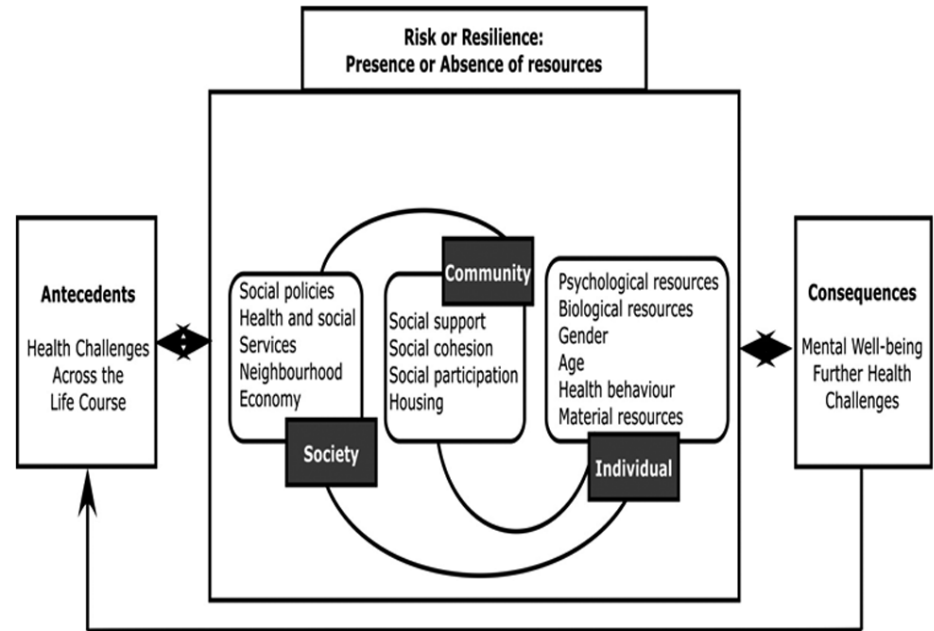


WINDLE (2011) DEFINES RESILIENCE AS 'THE PROCESS OF EFFECTIVELY NEGOTIATING, ADAPTING TO, OR MANAGING SIGNIFICANT SOURCES OF STRESS OR TRAUMA.

'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 FRAMEWORK (WINDLE 2011)



- **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.
- This guide 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
020914	Female	60-69	1-3	Second Level
WS320069	Female	60-69	1-3	RGN/RGM
010914	Female	60-69	1-3	Degree
080414	Female	70-79	4-6	Technical Vocational
040414	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, with my lifestyle, I suppose, really and, and the memory loss as such.
(080414)

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

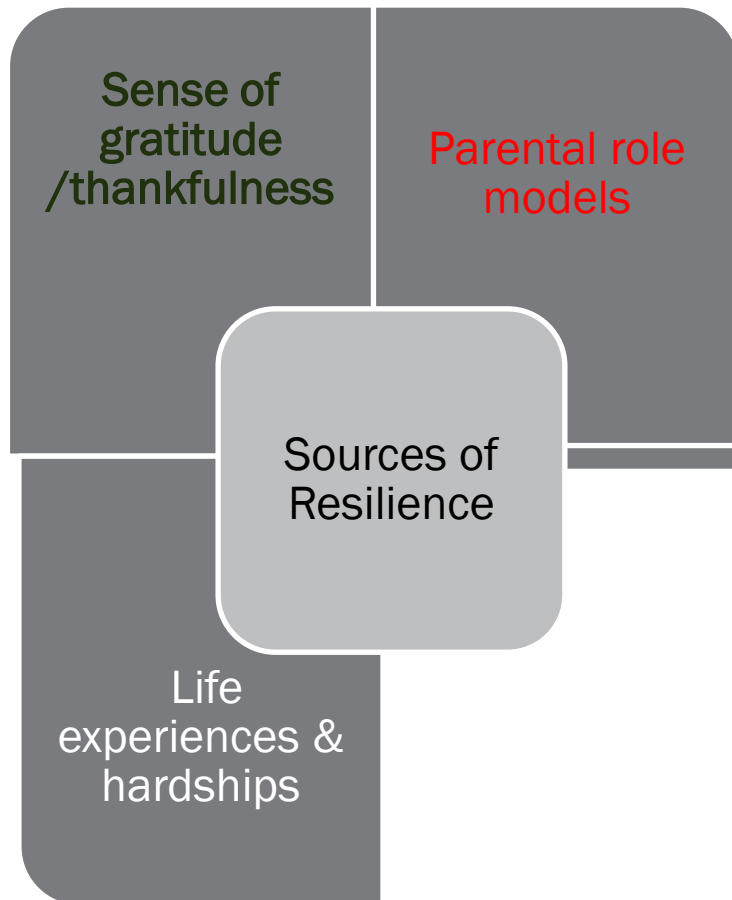
“That you can remember things, is it, I don't know.” (020914)

“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. (080414)

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 (010914)

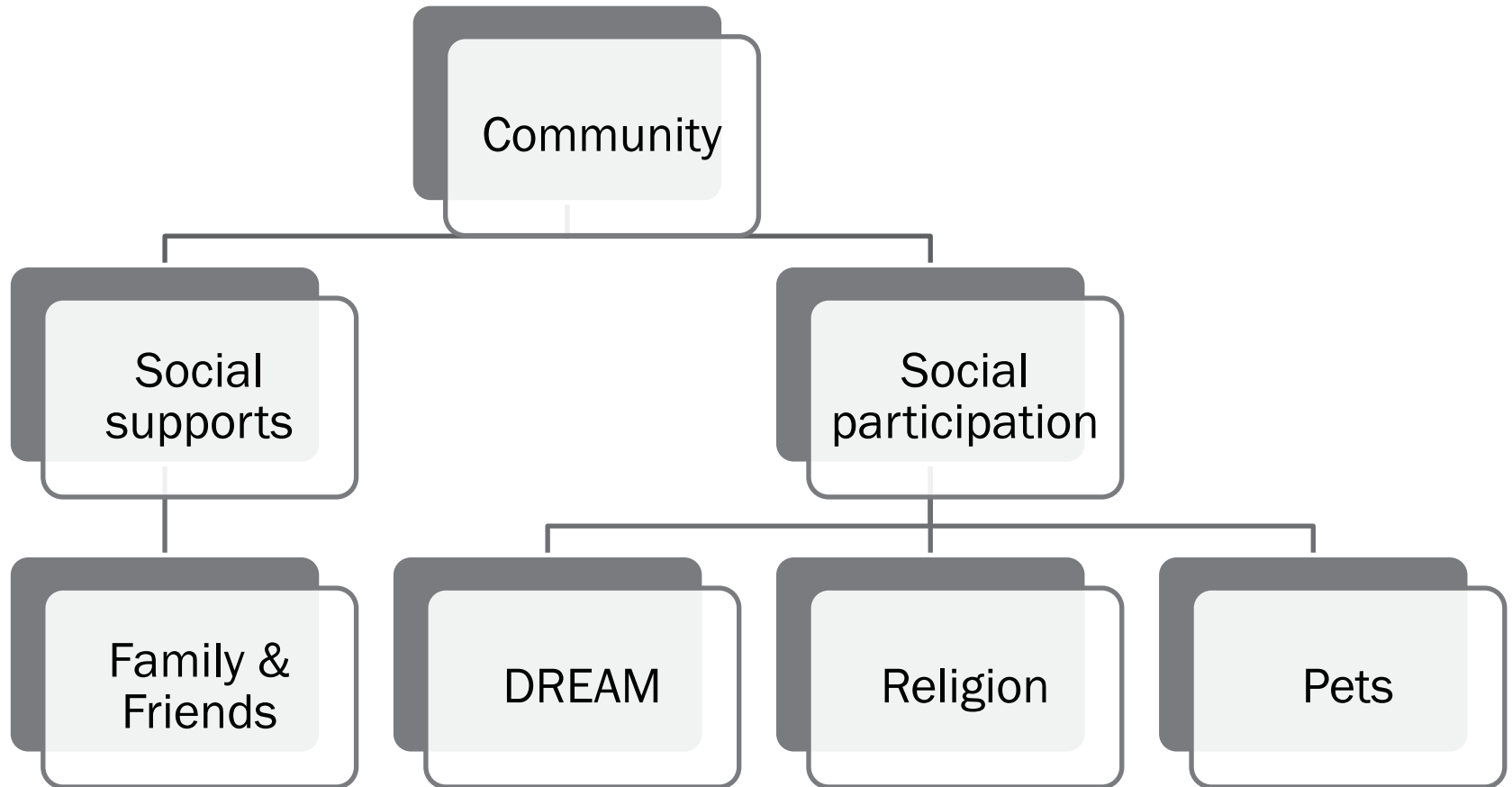
Where did you get that spirit from?

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

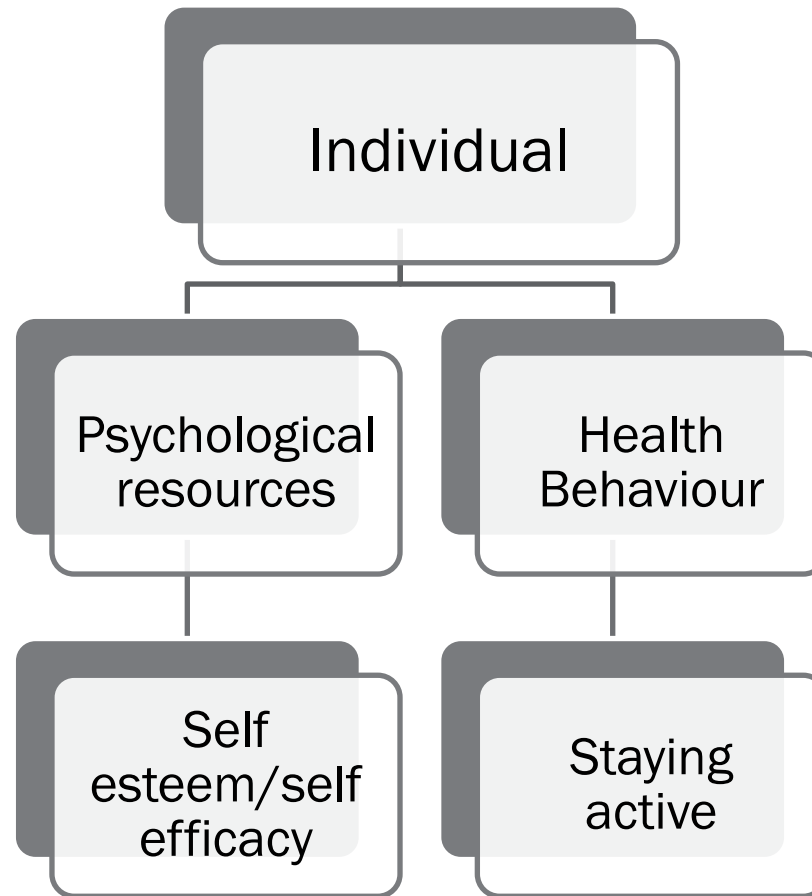
And it probably sounds silly, but that dog paves the way for a lot of things for me. Having a pet, it helps you...I feel sorry for her, she hasn't been down to see any dogs, she's a very friendly girl, so I take her to xxx beach and she knows the nice ones!...And they go to her. And the people then will 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)



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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)



CONCLUSIONS

- Most participants understood resilience and feel they are resilient
- Foundations for building capacity for resilience at
 - Community level -social supports and social participation, relationships matter, self efficacy and a belief in self, staying positive, having a fighting spirit
- Most feel they have the capacity to be resilient and building resilience matters.

