Carers' of people with dementia perceptions of resilience and the factors that support resilience

Professor Kathy Murphy
&
Dr Dympna Casey
Aim of presentation is to describe carers' of people with dementias perceptions of **resilience** and the factors that support resilience

“you have to be really strong to be able to cope”
Why resilience matters

Resilience refers to the ability to ‘bounce back’ and cope in the face of adversity, so for carers this is really important.

- We know from others that:
  - ‘resilience is the ability to see opportunities for personal growth in the midst of hardship may distinguish spouses who thrive as compared to others overwhelmed by caregiving demands’ (O’Rourke et al. 2010, p.990).
  - Three resilience domains—personal mastery, self efficacy and positive coping styles—have been found to mitigate the impact of stress on carer health (Harmell et al. 2011)
  - Some factors may help reduce the effects of chronic stress in caregivers such as social support, engagement in pleasant activities, self-esteem, positive attitudes towards the caregiving role, hope and optimism (Harmell et al. 2011)
  - Carers have a 20% increased chance of mental health problems (OECD 2015)

However little is known about the factors that carers identify as strengthening their resilience.
Grounding the Work

- To help us develop our interview guide and coding framework we drew on Windles work.

- Windle (2011) developed a theoretical framework that helps to understand the factors that impact on resilience building.
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.
Aim: to explore the factors that facilitate or hinder caregivers resilience when caring for people with dementia.

Methods:

- A descriptive qualitative study
- 1:1 interviews with 28 caregivers of people with dementia living in the community in Ireland.
- All interviews were tape recorded and transcribed verbatim.
- Transcripts were analyzed using the constant comparative technique and Windle (2012) resilience framework
- The criteria identified by Lincoln and Guba (1985) were used to ensure and maintain rigor. Ethical Approval was obtained from NUI Galway.
Demographics for Carers

Gender
- 6 men; 22 women

Age
- 3 carers >70 years; Youngest aged 43.
- 18 Rural; 10 Urban

Years of Caring
Years caring:
- 10 caring between 0 – 4 years
- 10 caring between 5 – 9 years
- 4 caring between 10 – 14 years
- 4 caring between 15 – 19 years
Themes

- Antecedences
- Factors that facilitate or hinder resilience at the individual level
- Factors that facilitate or hinder resilience at the community level
- Factors that hinder resilience at society level
- Consequences
Antecedence

Sense of gratitude / thankfulness

Previous Life experiences & hardships

Sources of Resilience
C6 I got to meet a number of carers where we had a weekend together, where you had time to sit down and chat about your own experiences and as much as the other carers felt sorry for me I was like, I don’t feel sorry for myself, the way I see is my situation is better than yours, you know, and I approached, I approached the whole thing in that way

C15 three years ago we went to an Alzheimer’s support group xxx and… and we listened to all those people talking and all of them had cases much worse that what we were dealing with because my Mother would have been very quiet in her Alzheimer’s and I remember (name) coming home thinking, ah Mam isn't too bad, sure maybe it's not, hers isn't as bad as theirs, you know, that sort of thing
Previous Life experiences & hardships

- Many caregivers were caring for their second relative with dementia

- Some were also trying to balance caregiving with employment

- C16: I had both my Mother and my aunt with Alzheimer’s… Now my sister, who is sixty-five, has got Alzheimer’s as well

- C6 …I've been trying to make the effort to look after him and just keep ticking over on the farm… I'm doing the best I can but there's not enough hours in the day to keep on top of everything and most of the time I'm good for not letting it bother me
Individual Psychological Resources

- Being Positive
- Fighting Spirit
- Humour
Being positive

C15... she starts this waffling on about whatever she goes on about and you say oh God I didn’t know that about her, you know, or she looks at photographs and she'd say ah that’s such and such a one, yeah there is, there is a very positive side to it, yeah. And it’s lovely to spend time with her even though she mightn’t realize it and I think that’s all very gratifying then because when she dies you have no regrets and you'll say look we did our best for her, we really got to know our Mam, you know, this past six and a half years and it's great that we were able to mind her and, as I said, give it back to her.

C11 But I’m now learning about my Mom, when she was young, she was a goer, my Mom, it’s lovely to listen to her, getting ready to go to a dance, telling me who she is meeting, and looking for her blue bra! Or telling me to go up and take a cigarette out of Tommy’s pocket, it’s in his left inside pocket, and only take one because he’ll know if you take two! So I’m meeting the person that I never got to see, and it’s actually wonderful.
Self esteem/self confidence

Having a fighting spirit

C6 ...I've stuck it out a long time because when I went at it I said right am I ready for this and I said right I am but you know, you know in your heart, more so than physically strong, but you actually need that too, you need to be really mentally strong to cope

C07 it's very basic food you do in the beginning, you know. I mean I got a book like and just try and work out, because she forgets all about cooking and everything like, all that's forgotten.

C08 I've had to fight for every bit of help I ever got from the HSE and anywhere, you know...You have to fight

Having a sense of humour

C15 the first thing you need is an awful lot of patience and, of course, you have to have a lot of good humour, you have to laugh.

C11... Or she'll see, what did she see now the last time, she had a kidney infection, millions and millions – millions of ants under the television, they were lifting it up! But you know it’s funny, I mean it genuinely is. Or there is always a man out the back, in a white suit, cutting down the trees, you know
Building a support Team

- Found the caring often falls mainly on one carer, other family members sometimes did not understand, at sometimes person felt they should not burden others but support essential to well being and continuing of caring
- It is right to keep social connections
Factors that hinder resilience at individual level

**Relationship pressures**

- C6 it reached a point where...it was either my Dad or my girlfriend,... even though she said no that all she wanted was that we'd live together or whatever, the signs were there, the signs were there that she wanted I suppose total commitment from me and I couldn’t give it because I was already committed to him long before I ever met her.

**High Stress**

- C7 normally I can cope with it fine, I mean I understand the situation and it's fine but there is times when, you know, you're probably stressed out and no cooperation and going against everything you want to do and then you feel in your stomach and a pain in your chest and you don’t know where you should be going.
Fear of future

Cared for mother, now sister

- C16 my sister now, she's just starting it and if she doesn’t stop there’ll be nobody coming within six months or a year, you know and yet she's only sixty-five but how do you tell them or her and you don’t want, like I don’t want to face it again, do you know what I’m saying.
Factors that facilitate resilience at community level

Community

Social supports

Support Groups

Health professional support

Family & Friends
Social supports – Family, Friends, Groups

C14 It’s a team like so you have to get a good team together to help you and your family. So I have a good team and I’m only a member of that team. That’s how I look at it.

C24 I’ve got five grandchildren who I sort of dote on so... They’re included and they sit upon Mum’s bed and... sing to her and kiss her and there’s one that’s two and one that’s three and they’re so good and “We love you, Mary” and I hope Mum... can hear it somewhere but she’s aware of the little ones.
Social supports – Family, Friends, Groups

C11 So I would have great support… I would have a very good friend, who also looked after her mother, she only died there about two years ago, and we would go over and we would have a really good bitching session – and euthanasia would be looking good! We’d have the coffee or the glass of wine, and we’d be giving out, and do you know you come away thinking “yea, ok I’m ready now, I can do this again” you know…But, no I have a great support… And it doesn’t have to be professional. The best support system I have are non-professional

• C14 it also means that I can go from the house as well. So not alone is she looked after the carer is looked after. So I get time too to go out and enjoy what I want to do as well.

• C07 There is someone to talk to you at every monthly meeting even if it is only about caring for yourself… meeting people in a similar people to yourself.
Health Professional Support

- C16 I found there was a team in there in XXX, they helped a lot ... And they helped with getting the services, I didn’t know where to start in the line of getting home help then or how to go about the packages and what was available or even the carers.

- But lucky enough I met good people that were willing to direct us in the right direction, it’s vitally important there, the district nurse was one of the old type, kind of a matron type, not one of these new ones that just pops in and out, she was actually willing to, to help in a very positive way, so I was very lucky to meet her I would have thought. So she kind of pointed us in the direction.
Factors that hinder resilience

Community

- No opportunity for social participation
- Lack of support from family, friends, health professionals
- Lack of knowledge and information
C07  I used to go out once a week or whatever, you know, and I'd have maybe, that's what, I love to socialize, I love to chat, to be meeting people, do you know like, guys that you're going to sit down, have a pint, maybe two or three pints, but if that only happened once a week, there'd be a lot of chat, some of it's rubbish but it's...It doesn't matter, you can't do that when you have to stay at home like.

C24 So basically it has put our life on hold, really, mine and me husband's. Do you know what I mean? We never go away together or anything like that.

C13 it's hard at time alright. You wouldn't get out or your stuck at home you can't get out and do what you want to do.
Lack of support

C16 ...and with me most of my sisters’ families were reared and gone so I found it that I used to say sometimes, well I still have them at home, where are ye, you know.

C8 I had to find out...Everything myself...I mean for years I had no help at all, you know.

Q; So you basically picked up your knowledge

- As I went along... Yea

C15: Well, you know, at that stage I gathered all the books I could about Alzheimer’s and read them and then distributed them to my brothers.

C11: Because until I contacted the Alzheimers, I didn’t know... You know I thought “oh you had Alzheimers, end-of, and you’re a bit doddery, and you couldn’t remember anything” and that was it... And there are so many different types of Alzheimers and dementia.
Lack of information

- C06 …need to be put in the loop about, you know, the financial aspect of what’s going to ensue in the coming years… if they’ve had to give up their job like I did. I mean you basically walk into the job clueless as regards your entitlements…

- C13 Well I go to him now and again (GP) but he doesn’t say anything, he doesn’t give any support like that really, he’s not in to Alzheimer’s.

- C07 I mean I will need, I will have to have help like, you know, and probably, if it ever really gets really bad I’m gonna have to have help and, you know, how to go about all that. Stuff you don’t know how to go about like I mean I didn’t know anything,

- C08 Well of course there is the legal aspect

Q; The legal

You know, power of attorney, and what else

Q; In terms of looking after… (wifes )’s affairs…I mean nobody ever told me about it, but I have it sorted, but nobody ever prepared me for it
Societal level

Stigma & Negative attitudes
Stigma and Negative Attitudes

- C16 So we actually let people know early that they had Alzheimer’s but what we found was, well people stood back then, people that would have come to the house normally

- INTERVIEWER: Stopped coming.

- Yea …They didn’t know how to deal with it. The same way when you brought her anywhere, no-one really approached her because they were afraid so that I think, you know, she'd have had six, maybe a year more, six months to a year more of more - life if people didn’t know she had it.

- C15 I think that eventually there will be something like a CNSs for dementia and things like that and somebody that’s out in the community, that’s there to talk to people because it's still sort of a taboo and people, I’m sure there's lots of people that don’t talk about it.

- C8 For people, I feel for people with dementia, Alzheimers, whatever they like to call it, people think “ah sure, they’ve got Alzheimers”…I feel they… write them off, “ah sure what can you do?”

Q; Mmm

I do feel that it’s like a, what’s the word I’m looking for? Like a prejudice or something, you know…They just think “oh, you know what can we do?” “There’s nothing, there’s nothing we can do for them”…Which is totally wrong, totally wrong.
Conclusions

- At individual level: Learning from life experiences; a sense of gratitude seem to be important resources for resilience.
- Foundations for building capacity for resilience at:
  - Community level: social supports from family, friends, groups and health professionals and social participation and relationships matter, so need to work to strengthen these.
  - Individual level: staying positive, having a sense of humor, and a fighting spirit.
- Society: remove stigma and negative attitudes.
- Most people have the capacity to be resilient and building resilience matters but all struggle at some stage and support brings people through.