

Recovery and Quality of Life

People with dementia and their carers

What do we know?

Making involvement meaningful

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We would like to acknowledge the contribution of Andrew Little to the C-DEMQOL study, a passionate supporter of Patient and Carer Involvement, who after our first Lived Experience Advisory Panel (LEAP) meeting, died following a short illness. He cared for his wife Marilyn, who had been living with dementia, for a number of years

Background – dementia, recovery and quality of life

Defining what recovery means for people with
dementia

Understanding quality of life for carers of people with
dementia (C-DEMQOL study)

Where is the overlap?

Making involvement meaningful

Dementia

- The number of people with dementia currently living in the UK is estimated to be 850,000 with a predicted increase to over 1 million by 2025 and over 2 million by 2051 (Prince et al., 2014)
- Dementia takes places in the context of a relationship, most commonly spousal or parent/child
- In 2012, there were 670,000 family carers of people with dementia in the UK (Alzheimers Society, 2012), whose caring contribution is estimated to be 44% of the overall cost of dementia in the UK, currently £26.3 billion (Prince et al., 2014).
- The outcomes of people with dementia and their carers, whilst different, are inherently linked. Family carers are a vital determinant of QOL and positive outcomes for people with dementia. For example, having a co-resident family carer exerts a 20-fold protective effect on risk of institutionalisation (Banerjee et al., 2003).

Recovery and QoL

- Concept of recovery has a variety of definitions and is contested.
- Systematic review (Leamy et al, 2011) identified five key components: Connectedness (with others) Hope, Identity, Meaning, and Empowerment (CHIME)
- Recovery capital (Tew, 2013)- viewing the person in their social context and assessing capital. Five distinct forms of capital (Economic, Social, Identity, Personal and Mental)
- QoL - appraisal of one's position in life, assessed in the context of own culture, values, goals, expectations, influenced by physical health and functioning, socio-economic status, physiological, emotional and social wellbeing
- Recovery of QoL (ReQOL) Brazier et al, 2015 - multi-dimensional (e.g. not exclusively focused on wellbeing) concerned with impact of mental health on QoL
- QoL in people with dementia and their carers

Recovery and dementia

Despite a supporting policy agenda (Department of Health, 2011), there is limited empirical evidence and guidance about what recovery means for people with dementia

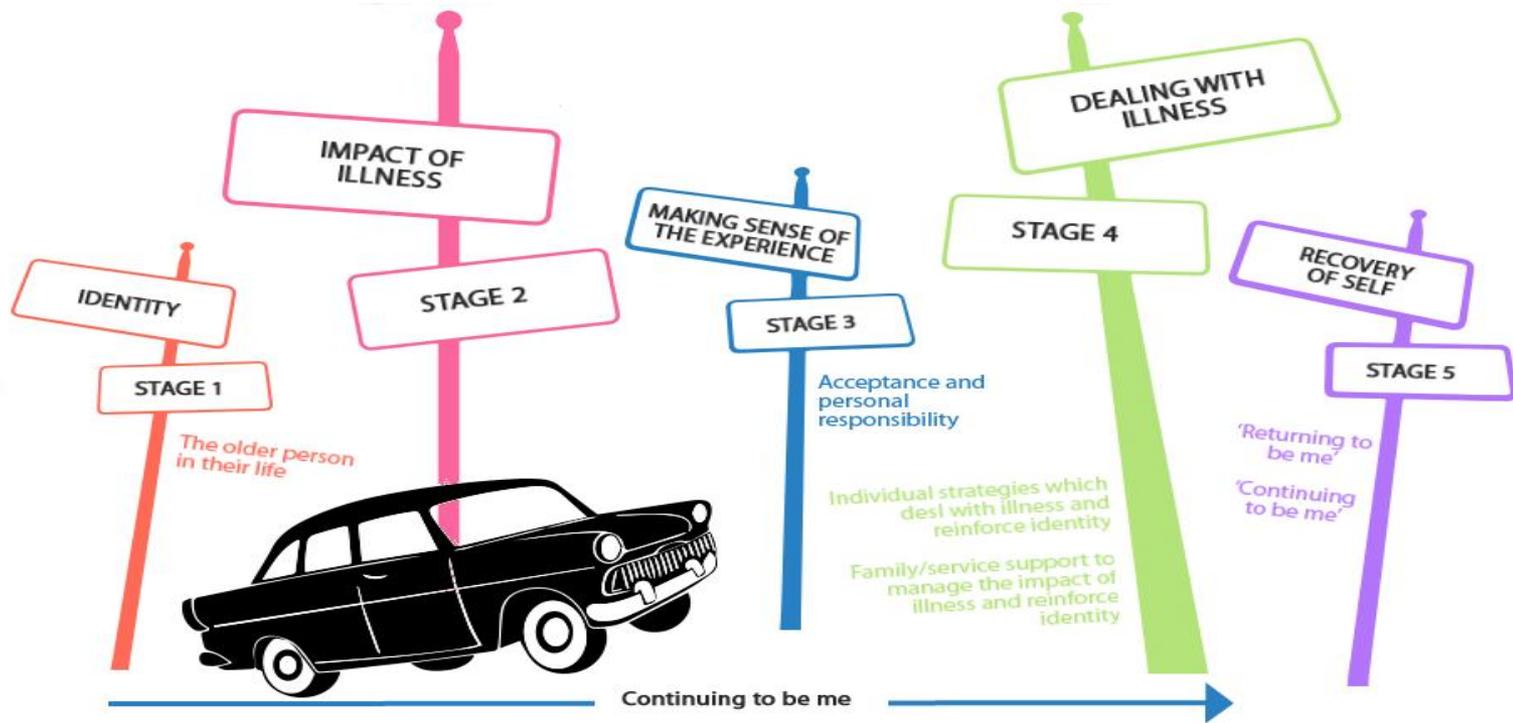
- Recovery and person-centred care (Perkins et al, 2016, Hill et al, 2010, McKay et al, 2012, Gavan 2011)
- Generating hope (Sole and Read, 2009, Hill et al, 2010, Woods, 2007)
- Recovery at diagnosis (Irving & Lakeman, 2010, Adams, Cheffey et al, 2013, Martin, 2009)
- Preliminary RCT on recovery-oriented intervention for people with early dementia (Jha et al, 2013). Significant change ($p=0.03$) was found in the WHO-5 (Heun et al, 2001) change scores, but not in other measures
- Facilitating self-management (Mountain & Craig, 2012, Martin et al, 2013, Cheffey et al, 2013)
- Providing opportunities for positive risk-taking, choice and service redesign (Irving & Lakeman, 2010, McKay et al, 2012)

Development of a framework for recovery for older people with mental health problems

Semi-structured qualitative interviews undertaken in 2010 with 28 service users, 11 of whom had a diagnosis of dementia as well as 11 carers, and analysed using grounded theory methodology. Two key research questions:

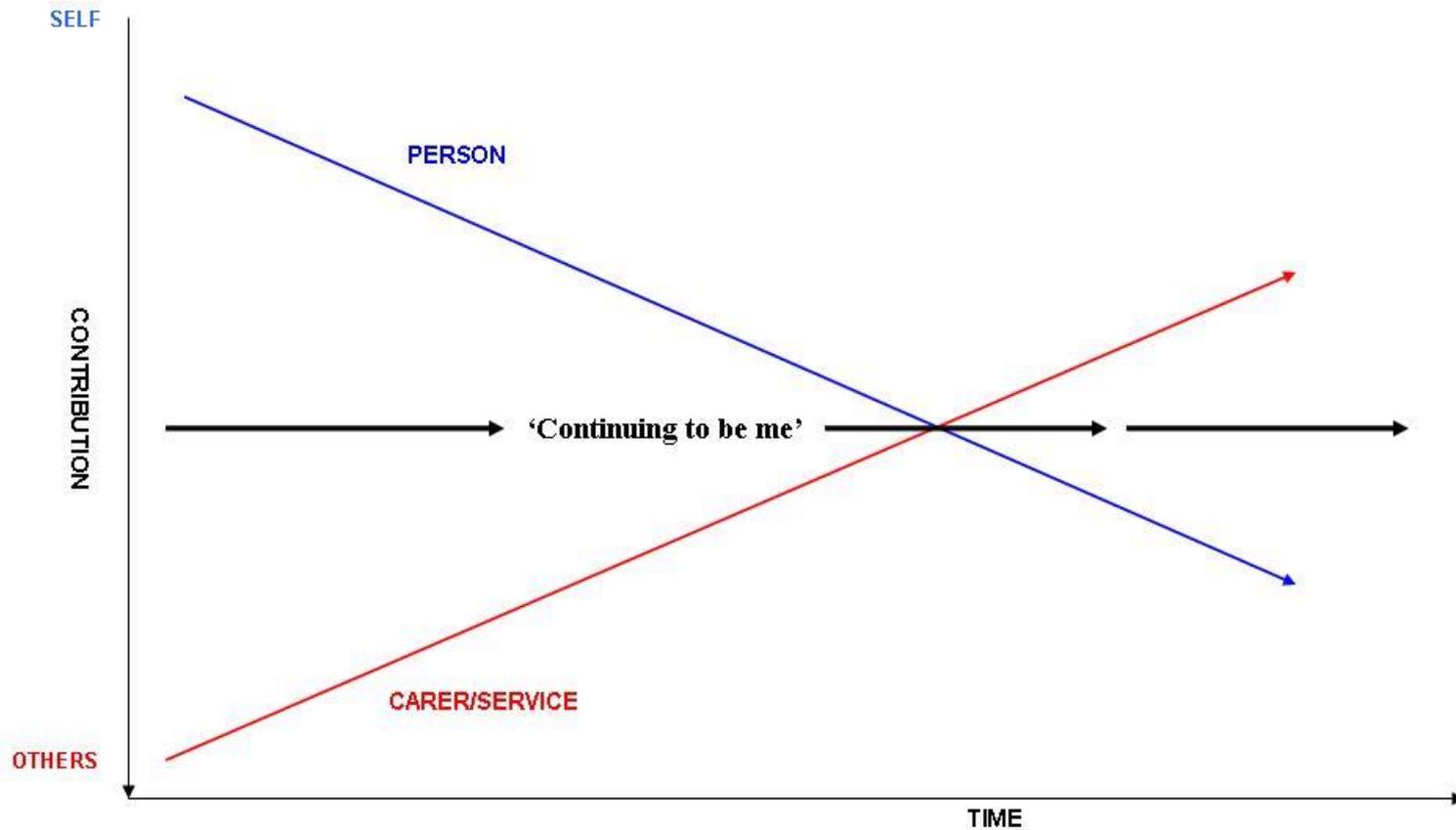
1. Are existing components of recovery meaningful to older people with mental health problems, including those with dementia?
2. Are there additional components of recovery which are specific to dementia, and whether these change as the illness progresses?

Framework of Recovery for Older People



Daley S, Newton D, Slade M, Murray J, Banerjee S, 2013, Development of a framework for recovery in older people with mental disorder, International Journal of Geriatric Psychiatry, 28, 522-529

Additional Components for People with Dementia



What does this tell us?

Similarities between older people and working age adults :

- The impact of illness
- the significance of personal responsibility
- specific coping strategies

Differences for older people :

- The significance of a established sense of identity
- Coping strategies which provide continuity and reinforce identity (Atchley, 1989)
- Reciprocal relationships and 'social capital'
- Impact of physical illness

Additional factors for people with dementia

- Changing experience over time
- The role of carers in the process

The C-DEMQOL Study

- The key aim of the study is to develop C-DEMQOL, a condition-specific questionnaire to measure Quality of Life (QOL) of family carers of people with dementia
- QOL - Carer's appraisal of position in life, assessed in the context of their culture, values, goals, expectations, influenced by physical health and functioning, socio-economic status, physiological, emotional and social wellbeing
- Seven stages over a 30 month period, starting in October 2015. Stage 1 was the development of a framework for understanding QOL in family carers

What we did

- We carried out individual interviews with 32 family carers and 9 staff and ran two focus groups with family carers (n=6) and staff (n=5)
- These were audio recorded and transcribed verbatim, and checked for accuracy
- 12 themes were identified from the analysis which were organised into three overarching categories; **Person with dementia**, **Carer appraisal** and **External world**.
- Used these themes to develop the items (questions) in the new questionnaire

Participants (n=37)

Characteristic	Range	Mean
Age	45.9 – 84.8 years	66.05 years
	Type	Number (%)
Gender	Female	24 (64.9)
	Male	13 (35.1)
Ethnicity	White British	32 (86.5)
	White Irish	1 (2.7)
	Indian	3 (8.1)
	Persian	1 (2.7)
Marital status	Married/partner	34 (91.9)
	Widowed	1 (2.7)
	Divorced	1 (2.7)
	Single	1 (2.7)
Relationship with the person with dementia	Spouse/partner	21 (56.8)
	Son/Daughter	14 (37.8)

Over-arching category one: Person with dementia

- **Relationship with the person with dementia**

'I think he's more like my child than my Dad now. He's like a big toddler.'

- **Change in the person with dementia**

'He will just explode, and he will shout and scream and his voice will go up and ...everything's our (family carer and daughter) fault.'

- **Demands of caregiving**

Over-arching category two: Carer appraisal

- **Personal freedom (do what you want to do)**

Yes, well, you know, coming to terms with the situation I'm in where I'm almost a prisoner, really.'

- **Acceptance of the caring role**

'You know, I say to him, "You'd have done it for me" and he would...I just think of it as, of course I would.'

- **Finding meaning**

- **Carer health**

- **Expectations of the Future**

Over-arching category three: External world

- **Evaluation of support**

We're trying to get some money from Social Services (to fund domiciliary support) and we're having a... battle.'

- **Weight of responsibility**

'It's the sense of responsibility for his life.'

- **Family and Social networks**

'The things that probably keep me going are external, our friends. We chatter on the phone and by messenger, email and whatever, texts.'

- **Role conflict**

People with dementia and their carers: Overlap with recovery & QoL

Recovery for people with dementia (Daley et al, 2013)	QoL : carers of people with dementia (Daley, Banerjee et al, 2016)	Recovering Quality of Life (ReQoL) Connell et al (2015)	CHIME Recovery domains (Leamy et al, 2011)
Identity	Relationship <u>with</u> person with dementia/social & family networks	Belonging/Relationships	Connectedness
Impact of illness	Finding meaning	Hope/Hopelessness	Hope
Making sense of the illness	Acceptance	Self perception (Identity)	Identity
Dealing with the illness: relationships & activities	Change in the person with dementia	Activity (meaningful/enjoyable)	Meaning
Recovery of self/continuity/expectations of the future	Delivery of care/weight of responsibility/evaluation of support	Autonomy/Choice/Control	Empowerment
Role of carers and change over time	Personal freedom (doing what you want to do)	Well-Being/Ill-Being	Well-Being/Symptoms
	Physical health	Physical Health	
	Expectations of the future		

Carer Involvement (PPI) within the C-DEMQOL study

- Role of the Lived Experience Advisory Panel in the research.
- The impact and experience of Involvement on the research from the perspective of the Carers and Researchers
- The experience of collaboration

Patient and Public Involvement (PPI) in C-DEMQOL

- Involvement an integral part of the grant proposal, ensuring the presence of the family carer voice throughout the study from design onwards.
- Thurstine Basset, recruited as Co-applicant with lived experience of care-giving
- Lived Experience Advisory Panel (LEAP) established
- Jean Southey designated Coordinator of LEAP
- “Involvement Log” of PPI activities kept.
- LEAP meet at key times during the research cycle.

C-DEMQOL and PPI in practice – stage 1

Review of literature and drawing out themes identified by Researcher and Co-applicant. LEAP discuss topic guides (October 2015)



Manual coding of 1 transcript with Researcher & LEAP group (January 2016) & agreement of initial coding framework with the involvement of Psychometrician.



Further completion by Researcher of 18 individual interviews and coding of transcripts



Review of the emerging themes and agreement of focused coding framework – also consideration of what else might we want to know, theoretical sampling (who else might we want to see?) (March 2016)

C-DEMQOL PPI in practice – stage 1

Completion of 11 individual interviews by Researcher

Review of overall themes and items (key items, behaviour indicators,, context, why important)

Review of draft conceptual framework, agreement of topic guides for focus groups (April 2016)



Researcher facilitation of focus groups x 2 (April 2016)

Agreement of final conceptual framework

Review of potential measure layout and item questions (May 2016)



Item-writing workshop with Researchers, Psychometrician and Co-applicant (June 2016)

The impact of Carer Involvement on the research. The Co-applicant's view

- Having my lived experience expertise as a carer taken seriously in the development and delivery of the research

“Being able to feed the lived experience carer perspective into the original proposal and having a ‘carer’ voice at the ‘top table’ at the Study Management Group”

“Being able to offer various key writings of carers and an initial framework for the researchers and working jointly with the qualitative researcher”

The impact of the Lived Experience Advisory Panel views on the research

- Validation of the emerging findings

“With the detail of the interviews we could reinforce things from our experience, we could recognise that we had all experienced that. The group influence could be seen from the different emerging themes.”

“We could come up with a consensus of what we have in common in relation to the responses from interviews and focus groups.”

LEAP member views of the impact of their lived experience on the research

- Making a difference to the research

“Each time our discussions were well documented in the notes and have changed and influenced the questions or items in the original questionnaire, adding things from our perspective so we felt heard and change happened.”

“It was an equal collaboration and I felt the researchers listened to all our views and took them into account. Every time the insights or perspectives of our experience as carers added something different for the researchers, changing how they were going to approach something; adding a different question, evolving and developing in a real way guided by experience.”

LEAP member views of the impact of their lived experience on the research

- Widening the conversations

“It was important to look at the cross section of getting participants such as going to poorer areas and we identified the BME angle that might be different.”

“Members of LEAP can ask questions: ‘are you capturing and wording things differently?’so they can really give their views.”

LEAP member views of collaboration with researchers on C-DEMQOL

- Commitment and being taken seriously

“Everyone around the table was engaged and generally wanted to make a difference to other carers and could express easily their similar experiences and were happy to share them. There was a respect for that and the support element; we are in it together sharing and knowing the frustrations (of caring) so there is more of a sympathetic view – “this is business and also personal”.

“The researcher was very open and easy to work with from the go. She was open to the lived experience point of view and was enthusiastic and keen to work with us...she really wanted to do it and that’s come across, so it’s an excellent collaboration.”

Researchers' views of the impact of PPI on the research

- The discussions and insights have directly influenced the direction and findings of the research

“The carers had excellent suggestions about item wording and content and this has been invaluable for creating well-written and valid items.”

- It has enhanced the rigour and defensibility of the findings
- It has allowed for the development of a robust conceptual framework which enables a solid foundation and structure for the new instrument

Researchers' views of the impact of PPI on the research

- It has helped us to truly understand the variety of carers experiences and how this fits or not with the academic literature

“Being at the LEAP group meetings has given valuable perspective to the issues identified as important from the academic literature and interviews...From a psychometric standpoint this is very important for understanding how to accurately capture and measure carers' thoughts and feelings about caring across different areas of their life.”

- This is critical in the validity of the new measure

LEAP “keeps us focussed” and “It keeps us honest to the real concerns of carers”

Thank you for listening

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and

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