



School
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“I have a good life, I just want to keep it”: Subjective understandings and objective evaluations of quality of life after a diagnosis of dementia

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Overview



- I. Quality of life and dementia- conceptualization and challenges**
- II. Study methodology**
- III. Participants**
- IV. Findings: QoL ratings, subjective understandings, main components and impact of dementia on QoL**
- V. Discussion and conclusions**

Conceptualising QoL in dementia



- Increasing tendency to investigate QoL and use it as outcome measure in research studies (Ettema et al 2005).
- Consensus that disease-specific instruments are more suitable than generic ones (Smith et al., 2005; Ettema et al., 2005) and growing numbers of dementia specific scales: DQOL, QoL-AD, ADRQL, DEMQoL, BASQUID, QOLAS, DCM, etc.
 - Scales differ in terms of the domains measured, how data is collected, the care setting where the scale can be used, severity of dementia of the individual (Ettema et al. 2005, Schozoel Dorenbos et al. 2007)
 - No single scale can claim superiority (Sloan et al., 2005; Moniz Cook et al., 2008)
- Some relevant areas - sense of autonomy and control, security and privacy, self determination and freedom, spirituality and giving meaning to life - not always covered by scales (Droes et al., 2006).
- Trends towards including some level of “subjectivity” in the evaluation of QoL but lots of challenges: access and consent, communication and reliability and validity

Literature findings

- PLWD evaluate their QoL in positive terms & more positively than caregivers (Smith et al. 2006; Banerjee et al., 2009)
- Only factor consistently associated with QoL is “mood”– Impact of cognition and functioning remains unclear (Banerjee et al., 2009; Hoe et al., 2009, Heggie et al., 2012).
- The subjective experience of living with dementia may be more relevant to QoL than objective symptoms (Hoe et al., 2009).
- Increasing interest in understanding how PLWD adjust to deficits and decline (Ettema et al. 2005, Byrne-Davis et al. 2006)
- Dementia may not be always the most significant issue in older people’s lives (Byrne-Davis et al., 2006, Robertson 2013)

Study's aims and methodology



Overall aim of the PhD was to explore the manner in which people with dementia and their care-partners (CPs), think and talk about their quality of life, their expectations and experiences with anti-dementia medication and the impact that the drugs have on their quality of life.

Aim of this presentation today is to address the following research questions:

- **How do, people recently diagnosed with dementia and their care-partners think and talk about QoL?**
- **How do they evaluate the QoL of the PLWD?**
- **How does dementia impact in their understandings and evaluations of QoL?**

Study Design

- Follow up exploratory design- baseline and follow-up interviews and QoL-AD measured at both points in time- Today' s presentation refers to the baseline interviews.
- 14 dyads (PLWD and Care-Partners) recruited from a Dublin-based Memory Clinic
- Data collection:
 - In-depth interviews using an interview schedule
 - Dementia specific QoL scale (QoL-AD)
 - Socio-demographic information sheet
 - Some relevant health information taken from medical records with participants consent.
- Written consent obtained from all participants - ongoing consent during the interview.
- Grounded theory techniques used for data analysis

QoL-AD

- The QOL-AD (Logsdon et al. 2001) is a simple self-report measure, comprising 13 items. Domains include “physical health”; “energy”; “mood”; “ability to do things”; “fun”; “memory”; “physical health”; “marriage”; “family”; “friends”; “money”; “person as a whole”; “life”.
- Each domain is rated on a four-point scale (scores range from 13 to 52).
- Example of question: “How do you feel about your physical health? Would you say it’s poor, fair, good, or excellent?”
- Can be completed by the PLWD and the carer (proxy)
- It has been used with people with mild and also moderate to severe dementia (Hoe et al., 2005).

Participants



PLWD (14)

- 8 men and 6 women (61-87)
- 11 retired, 3 home makers
- 4 participants were widowed - 10 married, lived with couple
- Most (10) had a diagnosis of Alzheimer' s Disease.
- Overall mean MMSE score was 20.3 (13-25)
- In 7 cases MMSE scores reflected a mild CI and in the other 7 a moderate CI

Care-partners (15)

- 9 women and 6 men (31-80).
- 4 working
- 10 spouses, 4 adult children (2 sons,2 daughters) and 1 sibling (sister)

Findings: Objective ratings

- QoL-AD scores of PLWD ranged from 29 to 47.
- As a group and in keeping with the literature CPs scores (mean score 35.8) tended to be lower than PLWD scores (mean score 39.1). The same trend was observed in individual scores.
- PLWD most often rated their QoL as either good or excellent (55%), whilst CPs were more likely to rate the PLWD QoL as fair to good (71%)
- Individual items:
 - Highest scores in relationships (marriage, family, friendships) and health.
 - Lowest scores in memory and functioning (ability to do things for fun, chores).
- Only one item where CPs tended to be more positive than PLWD – How has your **mood** been lately - would you rate your mood as poor, fair, good, or excellent?

Subjective accounts

- Normality – simple, normal, less demanding lives
- Great ambivalence in participants' accounts



"I have a good life"

- Good, ordinary life
- I am still ok (mildness of current stage)
- I can manage, coping



"I want to keep it"

- Uncertainty about the future
- Deterioration
- Not facing the future



- For many other circumstances equally important – e.g. widowhood, poor health and reduced mobility, etc.

Main components of QoL



- 1.FAMILY AND FRIENDS** (love and support if needed, getting on well and sharing activities, visits and contact)
- 2.KEEPING BUSY** (activities that structured their days and that they enjoyed, activities where they could contribute and felt valued, daily tasks and routines)
- 3.BEING INDEPENDENT** (mobility, being autonomous in their daily functioning, having control over things significant to them)
- 4.PSYCHOLOGICAL WELLBEING** (confidence, hope, happiness, joy of living, feeling well about oneself)
- 5.REMAINING HEALTHY** (managing health, pain and mobility)

Each domain encapsulated several meanings that connected the past, present and future

Some examples

FAMILY AND FRIENDS

“The children come in here, they throw their arms, they love you”

“If I phone him he is here, like that. If there is anything wrong I just phone him and he is here”.

“My wife obviously, the fact that I still love her, that’s really important, and that we get on very well”

“Well, I don’t see them [friends] daily, but they ring me almost everyday - and we are like that from when we went to school, and we have been friends since then”

KEEPING BUSY

“I like the bowling, its a lot of fun”

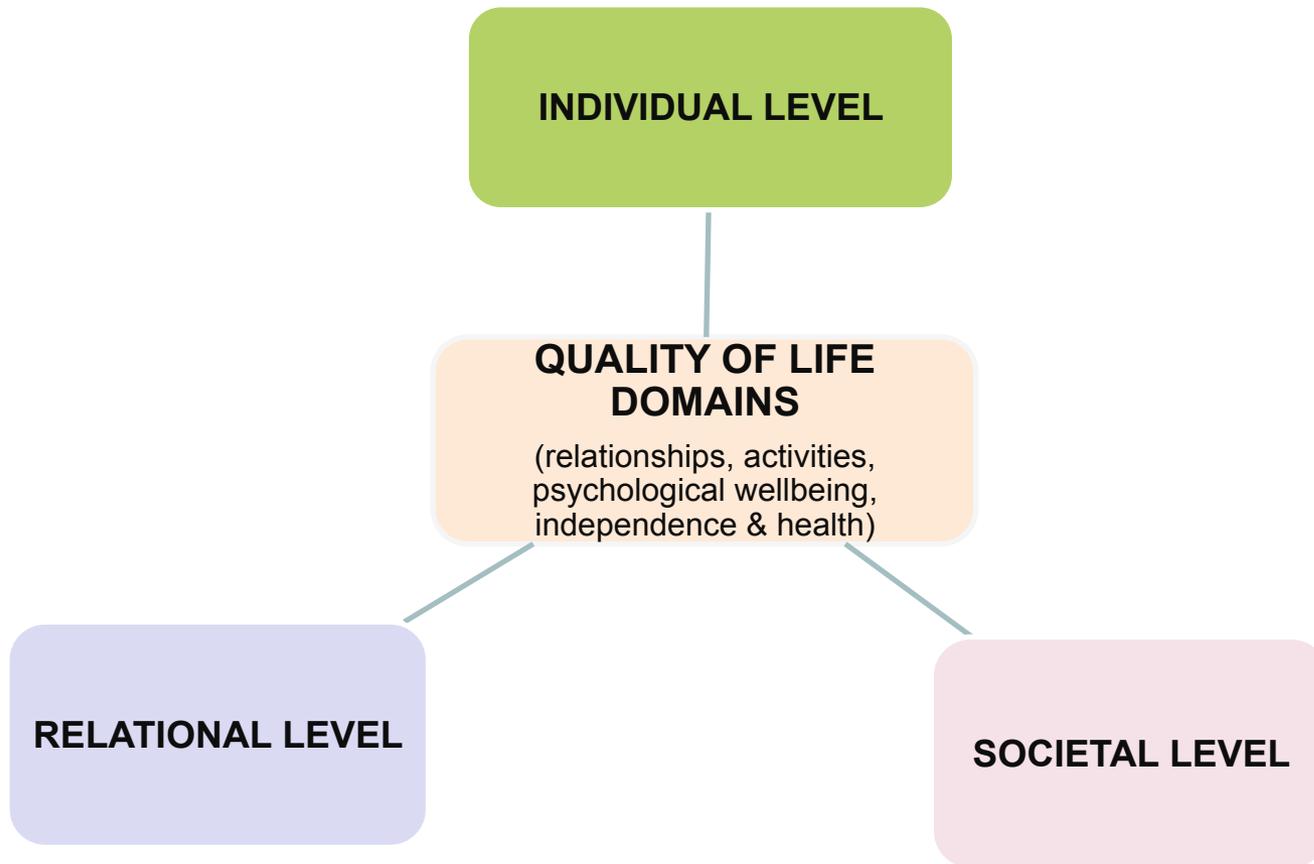
“We do voluntary work, we clean the church, and that’s once a week, just voluntary”

“One thing I would really like to show is how available we are for the children. One day, the son, rang up, can you collect the children in the school?”

“If she can continue to do her daily tasks, to get to town and get her pension, and the day-to-day routines she will be grand”



Impact of dementia on participants' understandings & evaluations of QoL - A 3D approach



1. INDIVIDUAL LEVEL

Life-long significance of domain and sense of continuity: values, priorities and lifestyle

“We are going to do everything that we always did, we are going to go on holidays, we are going to go out for meals, we are going to do everything that we always did - nothing is going to change”

Participants’ understandings and expectations of what is normal and acceptable at this stage of their lives and acceptability of the changes

“I am “the Mother” and, like, it is the mother that does that [provide help], like not the daughters done to the mother - it is difficult for me then to accept that I need help from them”

“She has changed a lot, where before she would be open to talk all day, now she just hates that, before she went with her friends and she did all the talking but now she goes but doesn’t talk, she still goes (...) but she is only quiet whilst before ... you know.”

2. RELATIONAL LEVEL

Complexity of the relationships with others.

“My grandson said, nanny, I used to give out because granddad, I would come in and he would ask me 20 questions, what are you doing? Anything and now I wish he would do it”

How PLWD are perceived and treated by family, friends and others (stigma, being afforded opportunities, etc.)

“I was afraid of his [partner] reaction to all of this (...) I sort of feel well I am not going to be able to keep up with him now, and all that kind of stuff. You know, and then if he gets fed up”

“I kept saying I am not well, because I thought that if they (friends) knew I could probably be left out”

“Neighbours had said to me “Oh you should be watching (name) on the bike” and I’d be terrified turning corners or whatever, but it is something I don’t want to take from him”

3. SOCIETAL LEVEL

Context and time: social construction of dementia

“Wasting away”

“Acting out of character”

“Inhuman, like the living death“

“If you lose your memory for goodness sake you are the walking dead”

“Because when you tell people that, they just see you in a different light... They see you with Alzheimer’s. That’s a word that should be banned in this country. It just conjures up all sorts of things.”



Discussion

- In keeping with literature, findings confirm that PLWD are well able to talk about and evaluate their QoL. Both the scale and the qualitative accounts suggested that this sample enjoyed a fairly good QoL.
- Specific domains identified are similar to those found in older people and to those included in the QoL-AD: relationships, activities, independence, wellbeing and health. Nevertheless, findings revealed the diversity of experiences and the complexity of the discourses that PLWD may hold when talking about domains. Also, the relevance of independence contrasted with the poor representation of this domain in most scales.
- The life course approach can be a useful perspective. Participants found it difficult to talk about their current QoL without placing it in the context of their overall lives and how things were before and how they expected it to be at this point in their lives. This places QoL as part of “on-going histories” (Robertson 2013) rather than as a snapshot picture of domains.
- The individual’s expectations, adjustment to and acceptability of deficits seemed more relevant in their evaluations than the objective deficits (Ettema et al 2005; Robertson 2013)
- Similarly how the person is treated and perceived by others and the impact of the social context on QoL are often overlooked and reduced to the quality of relationships or the adequacy and appropriateness of where the person is living.

Conclusions

- The study shows the merits and demerits of using a positivist and social constructionist approach.
- The QoL-AD is an easy to use and useful scale – nevertheless in this study it failed to capture the complexities and tensions found in the private voices of the participants.
- All participants were willing and enjoyed talking about their QoL, nevertheless qualitative enquiries are lengthy, resource intensive and often yield ambivalent findings.
- Combining qualitative and quantitative approaches can enable researchers capture a richer overview of the quality of life of people with dementia.
- The impact of dementia on QoL may require a dimensional approach including: personal level, relationships and social representations of dementia.
- Evaluations and interventions to improve quality of life of PLWD should take into account these complexities and richness found in the PLWD understandings and evaluations of QoL.



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