

## Challenges to Communication in Dementia Care Research: Our Experiences and Lessons Learned

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## Overview of the Presentation

- Definitions
- Communication when conducting research with people living with dementia (PLwD)
- Barriers to communication
- Strategies for overcoming these barriers
- Findings from a recent study on Quality of Life and Dementia in Residential Care
- Conclusions



***“The single biggest problem in communication is the illusion that it has taken place” -***

***George Bernard Shaw***

Communication is a fundamental aspect of all human relationships and part of our daily lives (Ritcher, Roberto and Bottenberg, 1995)

-It can occur either verbally or nonverbally - Several studies suggest that a high percentage of meaning in a conversation is conveyed non verbally (body language, postures, gestures, eye contact, tone of voice)

-Communication entails creating and sharing meaning

-During communication information and ideas are sent, exchanged or received, from one person to another or from the physical environment (Powell, 2000)

*-Good communication is a critical component of every stage in the research process especially in qualitative research where the focus is on meaning*

## What is Research?

- Research is a systematic investigation used to increase or revise current knowledge
- Qualitative research
  - a particular type of research that aims at understanding and describing the world of human experience (Myers, 2000)
  - involves an interpretive and naturalistic approach, qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them (Denzin & Lincoln, 2000)
  - can be defined as “a form of systematic empirical inquiry into meaning” (Shank, 2002). This implies that qualitative research is grounded in the world of “experience”. It looks into meanings and tries to understand how others make sense of their experience.

Communication is essential in all aspects of qualitative research, particularly in:

- 1 The conceptualization and operationalization of a study
- 2 Methodology development including ethical approval procedures, instrument design, sample recruitment and data collection and analysis
- 3 Writing the findings
- 4 Disseminating its findings.

## **Traditionally PLwD have been excluded from active involvement in empirical research.**

**Curiously some of the reasons for their exclusion are closely related to communication issues:**

### 1 Consent is a pre-requisite in research

Participants should be given sufficient information, in an understandable format to enable them exercise their right to make an informed decision about their participation. Consent should be voluntary, informed and in writing. (King's College & South London and Maudsley NHS Trust).

Has a PLwD capacity to consent?

What about those who lack capacity?

How and by whom can the individuals' capacity assessment be made?

How should the researcher proceed if the person is deemed incapable of giving informed consent?

## 2 Accuracy and reliability of the accounts

- decline in cognitive functioning, difficulties in verbal communication including word-finding difficulties, using incorrect words and attention
- loss of insight or denial / anosognosia (unawareness of their deficits) - for instance, in measuring QoL it has been discussed that although PLwD can answer questions, they are likely to give overly optimistic ratings (Selai, 2001).
- neuropsychiatric symptoms (paranoia, agitation, delusions, hallucinations, anxiety, etc.)

Can PLwD provide reliable and valid data about themselves?

**These communication problems have resulted in discrepancies in perspectives about whose views should be sought when conducting research in the area of dementia**

- Proxy Informants:** formal or informal care-partners/ observation
- Person living with dementia**
- Both?**
- None?**

Research has **extensively relied on proxy informants**, however

### 1 Proxy Consent:

- It cannot be guaranteed that decisions made by a proxy always accurately reflect the attitudes and values of the PLwD (Fisk, et al., 2007; Karlawish et al., 2000; Connell et al., 2001). - "Best interest" of Whom? ; respecting person wishes?
- Caregiver burden, age and personal characteristics have been found influential when making decisions about a relative with dementia

**2 Collecting information from a proxy**, for instance in the area of QoL, can be problematic (Smith et al., 2005)

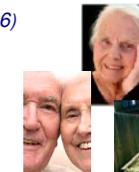
- PLwD mostly report on the "here and now", whereas relatives respond on the basis of both the past and current situation
- Proxies (both formal and informal) often underestimate the PLwD's QoL - Rates might be biased by the proxy's own expectations and belief system, their prior or current relationship and the burden of care
- Proxies tend to associate QoL with cognition and physical functionality

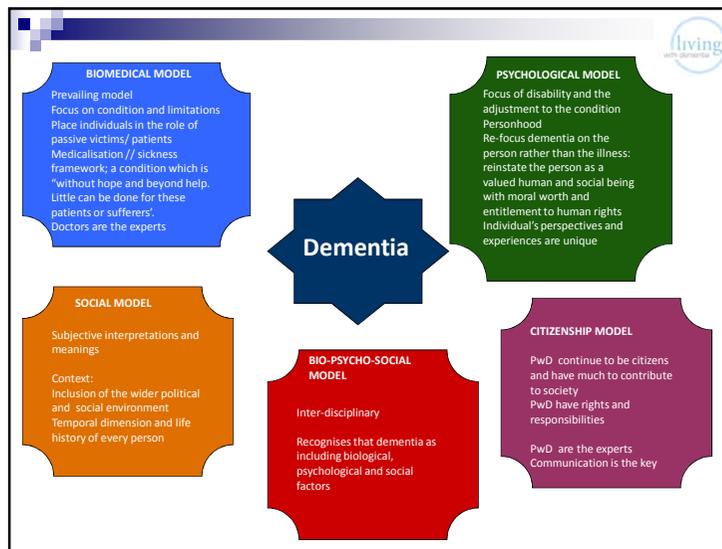
**Relying on Proxies whilst sometimes easier than attempting to actively involve a PLwD in the research process can pose several challenges**



*"The way we conceptualize dementia shapes what we see as legitimate needs, and structures what we see as possibilities for intervention"*

Munro, Small & Froggatt (2006)





**living with dementia**

## Alternative approaches to understanding dementia

Person **with** dementia vs. **Person** with dementia



PLwD as **active social agents and citizens**

*"Does the disease increasingly dominate my life or has the disease insidiously become a part of my life?" - Richard Taylor*

**living with dementia**

Recent years have witnessed a movement towards **eliciting the voice** of PLwD in research studies.

This has resulted in an increase in exploratory qualitative studies which have produced findings **now regarded as "legitimate accounts"** (Hulko, 2007)

Indeed nowadays PLwD are considered the **"experts"**

- An increasingly emerging body of qualitative work investigating about the "lived experience"
- Research has confirmed that PLwD can articulate feelings, concerns and preferences and provide evaluations of their health and quality of life - the subjective definition of QoL by PLwD represents the best way of understanding their priorities and experiences.
- However, people in early to moderate stages of dementia are more often involved
- Main challenge remains in relation to people with severe symptoms of dementia, a group we particularly attempted to include in the research study I will discuss

- living with dementia**
- Several strategies can be used to facilitate PLwD's involvement and participation in research:**
1. Using simple jargon-free vocabulary in the information sheet, consent form and during interviews
  2. Designing questions that are not double barrelled, are easy to understand and are not abstract
  3. Using others strategies to optimize communication, such as
    - (i) allowing ample time to respond,
    - (ii) offering assurance to participants should they feel distress finding a word or exposing an idea,
    - (iii) refraining from contradicting participants' statements or quizzing them about further details they can not remember,
    - (iv) providing cues (i.e. pictures or photographs) to participants that may help to trigger a response
    - (v) being conscious of non-verbal communication and other such nuances
    - (vi) validating the meaningfulness of the individual's experiences and reports
- (Beuscher, 2009).

# Results of the Quality of Life Inquiry



## QoL Study Research Questions

- What views do people with different levels of cognitive impairment living in a nursing home have about their quality of life?
- What is important to them, what makes them feel happy and conversely what makes them feel sad?
- Can a simple open-ended questionnaire be used to examine quality of life in people with a broad range of cognitive impairments (from very mild to severe)?
- Are there differences in self-reported quality of life in people with different levels of cognitive impairment ?

## Research methodology

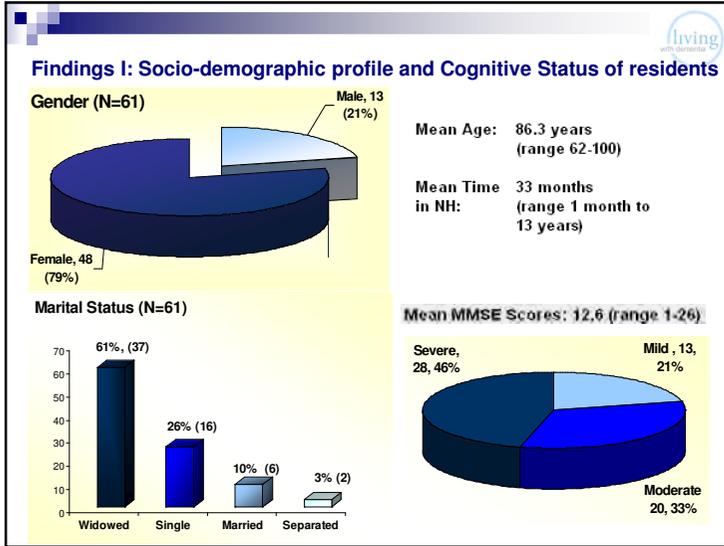
- **Qualitative - exploratory study**
- **Data Collection Instruments :**
  - Semi-structured interviews (open ended 15 item interview schedule\*)
  - Mini-Mental State Examination
- **Sample:**
  - 61 residents, 3 Nursing Homes
- **Analysis:**
  - Thematic analysis
  - Cases classified into three groups as per MMSE scores: (i) mild, (ii) moderate & (iii) severe

\* Some of the questions posed were based on earlier published studies on QoL and dementia

## Communicating with the Participants: main actions taken during the research process and in relation with consent

- Potential participants and their relatives were informed about the study by NH staff members and provided with a **written information sheet**. Two different information sheets were devised, using a clear and jargon free language.
- An **information letter** about the research was displayed (when possible) in the NH, so all staff and other non-included residents and families could be aware of the study
- Prior to commencing the interview, every participant was informed about the study's aims and protocol
- **Written consent** was sought **from all residents**. An easy to understand consent form was devised for residents
- For participants who had a severe CI, their **relative's written consent** was sought instead. In this cases **assent** was sought from the PLWD
- Consent was understood on **ongoing bases**, being revisited during the interview. Researchers were responsive to resident's body language and facial expressions. If signs of anxiety or discomfort (Dewing, 2007; Slaughter, 2007) appeared in relation to a particular issue, the question was left out. If these signs persisted initial consent was revisited. One interview was discontinued on this bases

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- Questions were carefully phrased and re-framed if the PLwD had difficulties in understanding.
  - Ample time to reply was given to every participant.
  - Researchers validated the meaning of every participant's story and listened to all they had to say.
  - Once the interview was finished, residents were brought back to a common area and, when possible, the researchers spent a few more minutes with them to ensure their well-being after the encounter.
  - Findings were fed back to NH managers and have been published and reported in the literature
  - In addition a booklet for Nursing Home staff & Family Caregivers about QoL in long term care was produced based on the research findings.
  - This booklet was distributed through Nursing Homes Ireland to a large number of stakeholders
  - The circulation of the booklet it is hoped will in some way help to improve QoL for PLwD in long stay care in Ireland.



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- ### Findings II: Main themes and sub-themes
- Social contact** (family, staff and residents)
  - Pleasurable activities** (structured and unstructured, outings and momentary pleasures)
  - Attachment/adjustment** (feeling at home, missing home, and connectedness)
  - Affect** (happiness, sadness/depression, loneliness)



### Differences and Similarities in Perceptions of Quality of Life across NH's residents with different levels of Cognitive Impairment

	MILD	MODERATE	SEVERE
<b>Family</b>	The most important thing in residents' lives	The most important thing in residents' lives	The most important thing in residents' lives
<b>Staff</b>	Very relevant, most good relationships. A few complaints	Very relevant, most good relationships. A few complaints	Little awareness
<b>Fellow residents</b>	Some new friends. Complaints about other residents	Little interaction	No awareness No relationship
<b>Structured Activities</b>	Great awareness and pleasure from it. Some complaints about boredom	Great awareness and pleasure from it. Some complaints about boredom	Unawareness, disinterest
<b>Unstructured activities</b>	Reading, music, TV, chatting, cards. Some missed past hobbies. Outings	Reading, music, TV, chatting, cards. Some missed past hobbies. Outings	Momentary pleasures: A cup of tea Having an ice-cream
<b>Feeling at home</b>	7 out of 13 Recollection of former homes missing their homes, neighbourhood, etc	6 out of 19 Recollection of former homes missing their homes and neighbourhood	5 out of 28 Greater disconnection and craving home Recollection of former homes missing their homes and neighbourhood
<b>Happiness</b>	Feelings of happiness, being in good form, having fun, enjoying life in the NH	Feelings of happiness, being in good form, having fun, enjoying life in the NH	Feelings of happiness, being in good form, having fun, enjoying life in the NH
<b>Sadness</b>	Accounts of sadness related to losses (deaths, house, health)	Accounts of sadness related to losses (deaths, house, health). Sadness in relation to age and being at the end of their life	Accounts of sadness related to losses (deaths, house, health). Some showed extreme despair
<b>Loneliness</b>	No accounts of loneliness	Some forms of loneliness	Extreme loneliness, feeling lost, abandonment and a quest for human contact

**1.- Attachment**

- Theme focused on extent to which participants felt “at home” in NH or connected to the environment where they now lived.
- The greatest number of reports of residents feeling disconnected and craving home was among those with a severe CI.
- Some attempted to make sense of where they were now living, claiming the NH was their work place or a temporary arrangement.

**Selection of quotes from the theme “Attachment”**



“I feel this is my home and nobody else’s”.  
(male 88, MMSE 26)

“I like to live here, this is my house. I’ve been here 9 years”  
(female 84, MMSE 22)

“Big shock to me from own home, you sit with your mouth closed all day”  
(female, 85 years, MMSE 26)

“We don’t live here – only visit here”  
(female, 87, MMSE 1)

“I lived at home, but this is not (home), this is a house”  
(female 66, MMSE 8)

**2.- Affect**

- Theme accounts for different positive and negative emotions emerging from analysis of interview data
- A large number of those with a severe CI seemed to be in quest of human contact
- Small minority of the participants revealed feelings of hopelessness
- A few reported feelings of virtual despair

**Selection of quotes from the theme “Affect”**



“I am happy when I see someone”  
(female, 94, MMSE 4)

“I have nothing to look forward to only carry on til my life ends”  
(female, 87, MMSE=12)

“I am very happy with my life here and the people I met”  
(male, 93, MMSE 22)

“Life in general is not the same, I admit it’s a bit lonely”  
(female 92, MMSE 15)

“Sometimes I wish I was dead because there is nothing for me in life at all. I can’t make anything out of life”  
(female, 90, MMSE=8).

## Main differences across groups

### ■ Main differences were found between those with severe CI and those with a mild CI

- Overall residents with a severe CI were less adjusted to NH's life, although several residents in all 3 groups craved for home  
*"I lived at home, but this is not (home), this is a house" (female 66, MMSE= 8)*
- Several residents with a severe CI felt disconnected from life in the NH including a feeling of disconnection from fellow residents and activities  
*"I don't know anybody (residents) in here. I spend my day in bed" (female 92, MMSE= 9)*  
*"I've never heard of any (activities). I don't know of any" (female, 66, MMSE= 8)*
- Most residents with a severe CI reported momentary pleasure (cup of tea, ice cream, etc), as opposed to structured activities or hobbies, as very important for them  
*"What makes you feel happy? A cup of tea" (female 95, MMSE= 4)*
- Residents with a severe CI often reported loneliness and a quest for human contact  
*"I hate having nobody here, I'd like to know where they all are" (female, 83, MMSE=3)*  
*"I will be glad to have more people coming in" (female, 84, MMSE= 4)*

## Conclusions (1)

- Findings support the increasing evidence that people with a CI and even those with a probable advanced dementia can often still communicate their views and preferences about what is important to them
- Whilst interpreting some narratives particularly those of people with a severe CI was challenging, qualitative methods enabled those with different degrees of CI to participate
- Regarding QoL and dementia, four key themes emerged following data analysis namely (social relationships, attachment, activities, and affect)
- Whilst some similarities exist across the three groups regarding perceptions of QoL, differences were particularly evident between those with a mild and severe CI

- In particular those with a severe CI appeared to crave human contact, and a large majority reported feelings of isolation and loneliness.

- Whether orthodox or not, we attempted to report on what was real and relevant to these elderly NH residents at the time

- Therefore we believe that for the most part their accounts should be seriously considered by NH staff, service planners, policy makers and researchers

- People with severe CI and advanced dementia are a very vulnerable group in nursing home care. Their unique and chronic needs warrant careful consideration

## Conclusions (2)

- Communication with people with different degrees of CI, particularly severe CI is not an easy task, it requires patience, perseverance, time, sensitivity and most importantly a conviction that what they have to say is relevant & probably valuable
- Communication / participation in research can be possible for this group. However, this has a double side: can those people communicate and how can we as researchers find different ways to facilitate participation and to interpret their voices?

### What we found helped the communication process

- The literature- building on other researchers' instruments
- Co-operation from Senior Management through good open communication about the potential value of the research (their not feeling threatened)
- Using in-depth one to one interviews
- Employing open-ended, simple and non threatening questions
- Allowing interruptions and letting people talk at length about the issues that were relevant to them
- Finding a setting to conduct the interview where participants felt comfortable and timing were very relevant
- Our own strong conviction that all PLwD have important things to say
- However, we are acutely aware that PLwD can be involved further in all stages of research and can be given more power in the research process



“The quality of my life is mine to determine, not necessarily yours to measure or understand. If you really must know about the quality of my life, just ask me! My answers to your questions wont be reliable, and wont be valid. But they will be true for me”.

(...)

“Please don't jump to the conclusion that I can't know or communicate how I feel about myself. Isn't it your job to figure that out when you can't “read” me?”

*Richard Taylor (2007)  
Measuring “the Rubs” of My Quality of Life  
Alzheimer's Care Today*

### Publications:

- Cahill S, Diaz-Ponce A, Coen RF & Walsh C. (2010) The under-detection of cognitive impairment in Nursing Homes in the Dublin Area. The need for on-going cognitive assessment. *Age and Ageing*. 38(1)
- Cahill S and Diaz-Ponce A (2011) “I hate having nobody here, I'd like to know where they all are” Can qualitative research detect differences in Quality of Life among Nursing Home Residents with different levels of Cognitive Impairment? *Aging and Mental Health*, 1;15(5):562-72.
- “Living in a Nursing Home: Quality of life. The priorities of Older People with a Cognitive Impairment” Pamphlet Compiled by Cahill S and Diaz A (2009) - Published with help of Home Instead and Nursing Homes Ireland



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