A multiplicity of sense making: Merging Clinical Assessment and Older Persons' Accounts of Fear of Falls and Social Isolation

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Overview of Presentation

- Brief TRIL outline
- Example of two ongoing Ethnographic Projects:
- Fear of Falling and Falls Research: Codes, Fear of Falling, Clinical Histories, Ethnographic Engagement, Cultural Context of Falls
- Ethnographic Validation of Social Network Scales and Social Isolation Case Study
- Conclusions and future developments

TRIL Centre

- Coordinated collection of research projects addressing the physical, cognitive and social consequences of ageing;
- Projected number of 600 participants (400 65 aged+ Fallers, 200 65 aged+ Controls) 300+ completed
- All informed by ethnographic research and supported by a shared pool of knowledge and engineering resources;
- Focus on falls, social connection and cognitive function
- http://www.trilcentre.org

Technology Research for Independent Living


A Trajectory of making sense:
Fear of falling
A fall is an unexpected event in which the participant comes to rest on the ground, floor, or lower level (World Health Organization, 2007)

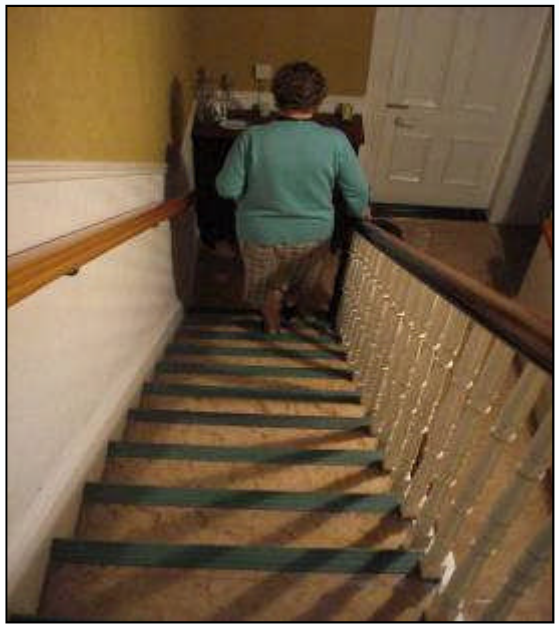
Clinicians Making Sense: Conventions, Codes, Accounts, Stories

" In their professional lives, physicians employ all the different varieties of reasons: **conventions** for routine problems, **codes** for their conformity to hospital rules, technical **accounts** for their consultations on difficult diagnoses, and **stories** for patients who lack the medical knowledge to follow the relevant technical accounts—"

- (Tilly 2006, in Zelizer 2006,p.532)

Clinical history taking: technical accounts

- Falls history including ‘trips’ and ‘stumbles’;
- Circumstances and location;
- Immediate post fall (e.g. able to get up, needing medical assistance?)
- Medications (including nonprescription) and alcohol;
- Intervention (e.g. physio)
- Fear of falling (FeS)



Measuring Fear of Falling: Conventions

- Fear of falling (FOF) is a major health problem among older people in the community who have fallen but also in older people who have never experienced a fall;
- Tools measuring FOF include Falls Efficacy Scales (FeS) that assesses the degree of perceived self-efficacy at avoiding a fall during basic activities of daily living (ADL);
- ADLs include: *personal hygiene, dressing, preparing food, getting in/out of chair/bed; walking inside the home; answering telephone; reaching high cupboards; light housekeeping; light gardening or hanging up the washing;*
- The modified FES (mFeS) includes four additional questions about outdoor activities including simple shopping and crossing the road.

Codes

"While self-efficacy beliefs can predict activity and dependence, these scales focus entirely on the functional implications of falling risk, and do not assess emotional or socio-psychological **aspects of fear of falling**" (Yardley 2004, p 198).

Older Persons and Falls: Stories through ethnography

Multiple household visits to:

- Explore older persons 'life worlds' including their **perceived challenges and coping strategies**;
- Access older persons' perspectives on quality of life, well being and ageing in place;
- Place above within life history and cultural context of growing older in Ireland.

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The social context of falling

- Observations so far, suggest that participants are as fearful of ***social implications of falling, or unsteadiness or dizziness, as physical injury/pain etc***.

- **Social implications include:**
  - • ***embarrassment*** : "it's just so awful, falling down in the street like that";
  - • ***loss of social standing particularly if the participant has lived in the neighbourhood most of their life***: " I won't be Terry anymore but 'him that falls'";
  - ***fear of losing personal autonomy complicated by ageist attitudes***: "see if I'm down [on the ground] I've got to get up quick even if I'm fair shook otherwise the word will be out that Joe's losing it, see, he's going down the pan, so I have to keep going.";

The cultural context of falling

- The current generation of older adults in Ireland is accustomed to dealing with injury and sickness in the home:

  "In those days people did not go running to the hospital for every little thing".

  They only report a fall when it results in a major injury;

- There is a sense that it is their responsibility to avoid falls;

- However props are not always accepted. A person with balance problems explains why he would not use a walking stick:

  - *"Well that's a matter of pride, like a last resort. It's sort of like giving up, something about being old and having sticks".*

Negotiating Different Accounts Of Fear of Falling

- FeS may identify routine activities that older person may most fear (e.g crossing the road);
- Spending time with older person in their life world may reveal the 'why';
- Placing the 'why' in wider cultural context may help understand the 'why';
- So FeS may need psychosocial as well as functional items?

The Ethnography of Social Isolation: A Qualitative Validation of the Lubben Social Network Scale

Second Example of Ethnographic Studies within TRIL

Lubben Social Network Scale

- The Lubben Social Network Scale (LSNS) is instrument designed to measure social isolation in older adults by measuring perceived social support received by family (relatives) , neighbours and friends which typically takes 5 to 10 minutes to complete.

LSNS (continued)

- It measures the size, closeness and frequency of contacts of a respondent's social network. It was originally developed in 1988 and was revised in 2002 (LSNS-R) along with an abbreviated version (LSNS-6) and an expanded version (LSNS-18). The LSNS is used at Tril, along with other important measures.

LSNS-18

- ***FAMILY*** *Considering the people to whom you are related either by birth or marriage…*
- *1. How many relatives do you see or hear from at least once a month?*
- 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more
- *2. How often do you see or hear from relative with whom you have the most contact?*
- 0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always
- *3. How many relatives do you feel at ease with that you can talk about private matters?*
- 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more
- *4. How many relatives do you feel close to such that you could call on them for help?*
- 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more
- *5. you about it? When one of your relatives has an important decision to make, how often do they talk to*
- 0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always
- *6. How often is one of your relatives available for you to talk to when you have an important decision to make?*
- 0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always

LSNS-18 (continued

- **NEIBHBORS:** *Considering those people who live in your neighborhood….*
- *7. How many of your neighbors do you see or hear from at least once a month?*
- 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more
-
- *8. How often do you see or hear from the neighbor with whom you have the most contact?*
- 0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always
- *9. How many neighbors do you feel at ease with that you can talk about private matters?*
- 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more
- *10. How many neighbors do you feel close to such that you could call on them for help?*
- 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more
- *11. When one of your neighbors has an important decision to make, how often do they talk to you about it?*
- 0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always
- *12. How often is one of your neighbors available for you to talk to when you have an important decision to make?*
- 0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always

LSNS-18 (continued)

- **FRIENDSHIPS:** *Considering your friends who do not live in your neighborhood….*
- ***13. How many of your friends do you see or hear from at least once a month?***
- 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more
-
- *14. How often do you see or hear from the friend with whom you have the most contact?*
- 0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always
- ***15. How many friends do you feel at ease with that you can talk about private matters?***
- 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more
- ***16. How many friends do you feel close to such that you could call on them for help?***
- 0 = none 1 = one 2 = two 3 = three or four 4 = five thru eight 5 = nine or more
- *17. When one of your friends has an important decision to make, how often do they talk to you about it?*
- 0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always
- *18. How often is one of your friends available for you to talk to when you have an important decision to make?*
- 0 = never 1 = seldom 2 = sometimes 3 = often 4 = very often 5 = always

LSNS- Justification and Use

- *Low scores (<30) on LSNS 'have been correlated with mortality, all-cause hospitalization and depression'*

(Lubben, J., Gironda, M. : 2004)

- *Increased awareness of the importance of social networks led to 'proliferation of measurement scales, some which lack the adequate validity and reliability'*

(Lubben, J., Gironda, M.: 2003)

Aims

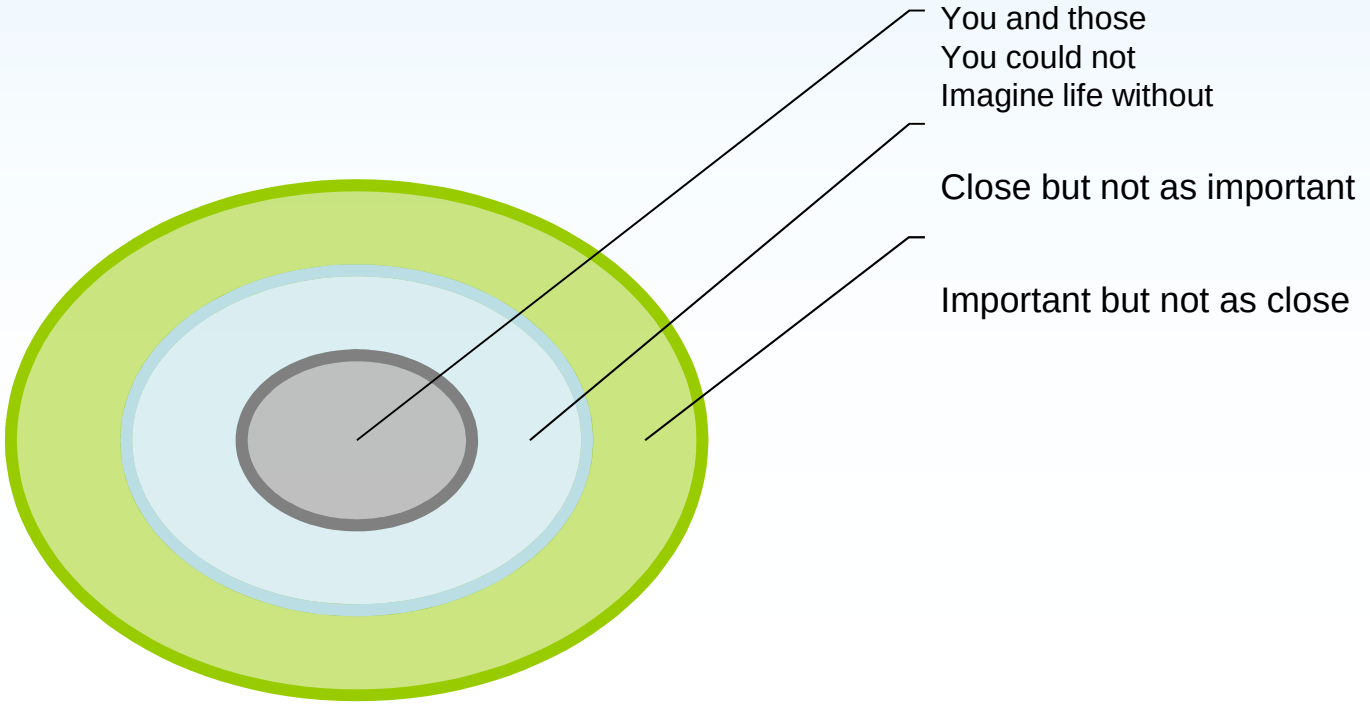
- Main aims:
  - Capture cultural aspects of living in Ireland
  - Deepen our understanding of social relationships in Ireland
  - Capture dynamic changes in individual social networking
  - Develop further our understanding of social isolation in Ireland
- The ultimate aims:

  is to establish the *sensitivity* and *specificity* of the LSNS as a clinical diagnostic tool of the geriatric syndrome of social isolation
- ***Develop and administer a TRIL diagnostic tool- Culturally Sensitive and Ethnographically Informed***

Methods

- Visit-1: Life History.
- V-2: Social Engagement/ Closeness
- V-3: Social Isolation
- V-4: LSNS and House Plans/Daily Activities

Closeness Diagram



Recruitment *Up-date*

- 7 participants contacted
- Scored less than 30 on LSNS
- 1 declined
- 1 physical health difficulties (postponed)
- Blind Study- LSNS score

- On average 1 in every 36 TRIL participants will have a LSNS score >30

- 6 completed
- 26 home visits
- Completion Date of Research January 2009?

Results to date

- Increase of 10-15% on all of all second Lubben scores.
- Possible causes/theories?

1. From clinic to home?
2. Therapeutic Ethno Effect?
3. Engagement with Ethnographer?
4. Time taken?
5. Different administration?
6. Problem with the LSNS?
7. Other causes as yet unidentified.

Meeting at the cross-roads between Elphin and Tulsk

- Setanta* is 6 ft 4, and about 16 stone. He lives alone in his ancestral family home. He has lived there all his life, he has three children and retired from farming in 1992

* pseudonym

Key Biographical Information of one Lubben participant

- Born 1936
- Leaves School at 14
- Marries Alison at 32 (1968)
- 4 children by 1971 (one child dies at birth)
- Alison diagnosed with MS 1971
- Mother dies in 1971
- Father dies in 1976
- Retires from farming in 1994
- Alison dies in 2007

Dependency?

- *My whole life was the carer. That was my life. My life was to look after her. There was no else to do it, I had retired from farming. Around here all the neighbours were gone, everyone had died…Then Alison died and I was lost. I'm lonely Cormac… I am lost without her, she was my whole life…*

Life for Setanta now…

- I don’t see that many people during the week. The phone is my biggest social outlet. I spend most of my day in the garden, or on the phone, or if the weather is bad trying to watch the tele or on the computer. I prefer being in the garden…

Setanta's Results

- Family
- Score: 23
- Neighbours
- Score: 8
- Friends
- Score: 15
- Total: 46
- Original Score <30

Next Phase

- Further 20 participants
- Developing support systems for those identified
- Continued validation of Lubben scale
- Development of TRIL scale, reflecting the overall findings of the ethnographic encounters
- Further longitudinal study of similar cohort