



ERU Collaborations with TRIL Strands

The ERU team are involved in ethnographic projects within three principal strands of TRIL — Falls, Social connection, and Cognitive. A number of within-strand projects are underway that capture the understanding and perspectives of TRIL participants from within the context of their lives in their homes, communities, and clinical settings.

Falls Strand

In collaboration with the wider TRIL research team, Falls strand ethnography includes the following projects, all based on ethnographic study of volunteers in the clinic and their homes.

Ambulatory Monitoring

To understand why people are falling or having black outs, some TRIL participants are undergoing ambulatory monitoring. This entails carrying out every day activities whilst wearing an appliance that records physiological readings (such as heart rate or blood pressure), usually over 24 hours. A TRIL ethnographer spends an extended period of time with the wearer of the monitor to help further understand the following research issues:

Regarding the monitoring process, how instructions/guidance offered in a clinical setting are implemented in the home/wider environment;

Wearer's understanding of and interaction with, the monitoring device;

Wearer's sense of ownership of the device; Impact of wearing the device on every day behaviour.

Interim findings will be reviewed prior to the planned Falls home trials of the monitors (Summer 08).

Household Falls Narrative and Management

Understanding family/household dynamics around falls is important as this may impact

on how home based, health technologies are perceived, received and used within the home setting. An older person's account of their falls' history and management, may not always concur with that of a family member. What is recounted in a clinical setting may differ from what is said and observed in the home setting. During household visits, the ethnographer considers accounts of both the older person who fell and also significant others (e.g. family/friends). This helps to capture a *comprehensive narrative* of the event and adds understanding of negotiation between older people and family members in the prevention/management of falls.

Ethnographic accounts are examined in relation to:

Specific language (e.g., trips, falls, spills, dizzy, muzzy, 'head popping', 'destroyed myself', 'stumble, drop, 'queer turn', fizzy, fuzzy, 'not myself', 'swooshing in the head' etc.)

Qualifying statements (e.g. 'just a little', 'not much', 'nothing really', 'fearfully terrible'; 'very frightening', 'couldn't understand it' etc.)

Falls Characterisation Project

With TRIL clinicians, ongoing research is being conducted on the psycho-social aspects of falls and their relationship to fear of falling.

Social Connection Strand

There are also several projects that involve the use of ethnographic research in the homes of volunteers participating in the Social connection strand of TRIL research.

Building Bridges

This project aims to explore new ways to maintain, stimulate and increase the social activities and interactions of older people through the use of both existing and new technologies. It has had ethnographic involvement from the start, with the ERU being involved in Focus Groups, and Entry and Exit interviews with research volunteers. This involvement is to continue with TRIL participants over the next six months as trials begin.

Many older persons, like this TRIL participant, are proactive in improving their health: "They say I have a touch of osteoporosis and exercising is supposed to be good for this."

Ethnographic Validation Project As indicated earlier (p. 3), the relationship between social isolation and loneliness is not fully understood. This new project will examine in greater detail the Lubben Social Network Scale, which has been adapted and is being administered at TRIL. The ERU and the members of the Social Connection Strand will have contact with TRIL participants who have achieved a low Lubben rating, and conduct additional exploratory ethnographic research to validate this score within the context of their home and social networks.

Ongoing Feedback

More informally, the ERU continues to provide feedback to the Social Connection Strand on the quantitative and qualitative data recorded at TRIL. The nature of the ERU's involvement at TRIL has also allowed us to feed back observation on how data is actually recorded.

Cognitive Strand

Ethnographic observations from the home and clinic help to inform ongoing research within TRIL's Cognitive strand. The following project, which developed from collaboration with Cognitive strand researchers, is just beginning.

Irish Elders' Beliefs, Strategies and Practices to Improve Cognition/Prevent Dementia

Alzheimer's disease, according to a U.S. study, is the disease most feared by persons 55 and over. By age 80, one out of five Irish elders are predicted to have this or another form of dementia. Given the expected increases in sheer numbers of older people, services for this population will demand serious bolstering. Some researchers believe that stigma associated with dementia in Ireland may have led to neglected funding of needed services.

Little is know, however, about what Irish elders themselves know, think and feel about dementia. This new ethnographic study will address these questions within its ongoing ERU research. The study will also examine how much control participants feel they have over their memories and in preventing Alzheimer's disease or dementia, and whether they are deliberately employing specific strategies to prevent them. Even where they are not deliberately trying to improve their cognitive health, their everyday behaviors and life styles may inadvertently contribute to it; this too will be explored through ethnographic observations and interviews with TRIL participants. Finally, the study will examine how socially well connected participants are since previous research suggests strong social networks may improve people's cognitive performance.



EthnographyMatters

SOME THOUGHTS ON ETHNOGRAPHY Dr. Athena McLean

Ethnography, though vital to anthropology in its studies, cannot be equated with it. Ethnography is a method used by professionals from a wide number of disciplines that examine various aspects of the human condition. Its broad appeal is in gaining unique knowledge directly from the perspectives of the people being studied. But even in ethnography there are competing views. The following thoughts were stimulated by my return from the annual meeting of the American Anthropological Association this past December, 2007.

Ethnography as method

Having recently returned from the annual meeting of the American Anthropological Association, I am reminded that ethnography cannot be equated with anthropology. It is *less* because ethnography is not a discipline, but a methodology to learn about people's lives from the people themselves. Ethnography is also *more* because it is used by researchers from diverse disciplines to supplement or elucidate their statistical or clinical findings. Disciplines as diverse as sociology, cultural geography, education and social work have all turned to ethnography to better understand how people address the complex challenges of the human condition. Observing how people live, and listening to how they talk about their lives and worlds offers a unique lens into the foreign, the unusual, and even the mundane. This often stimulates unforeseen paths of inquiry. What may be lost in breadth is gained in focus. The power of ethnographic work lies not in the number of cases or sites visited, but in the *validity of its interpretations as convincing* and its *implications for others* caught in similar predicaments. As a mathematician (and senior level policy advisor) recently told me, the *specific* struggles of *real* persons influences him far more than statistics about *faceless* thousands. Paired together, the two methodologies hold immense persuasive power.

Competing schools of ethnography in anthropology

How ethnographers go about gaining knowledge, however, will vary with their training. There are countless guidebooks on how to conduct ethnographic field work, but also schools of training that question the very value of guidebooks. In anthropology, for example, a dominant school of thought discourages coursework in ethnographic methods to avoid predisposing students to "cookbook" methods that might impede their own unique insights of how to proceed in their research.



Researchers at the Falls Strand Data Clinic, St. James Hospital, Dec. 17, 2007. Physicians, nurses, psychologists, engineers and social scientists worked together to share their perspectives in "making sense" of ethnographic data.

Instead, students are exposed to a vast literature of published ethnographies based on research to stimulate their imaginations. A competing approach, however, requires students to follow an intensive study of qualitative, and often quantitative methods, to enrich their repertoire of approaches for collecting data. Most graduate programs lie somewhere in between. Approaches to understanding the human condition are as varied as the condition itself...

Differences in ethnographic practice among disciplines

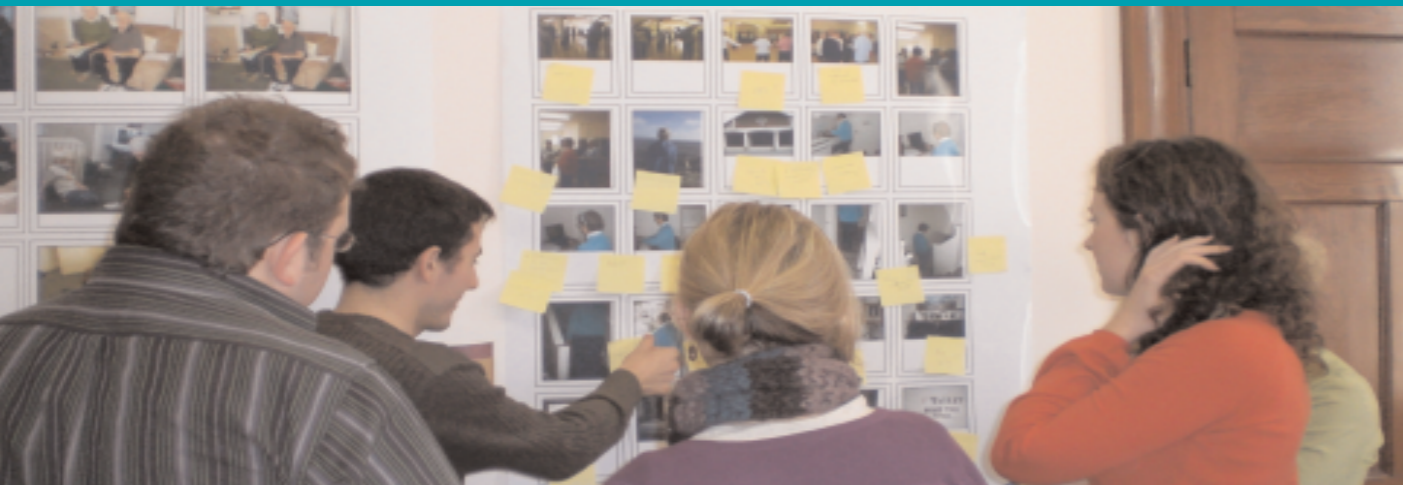
Over the years, I have benefited from collaborating with ethnographers from other disciplines. What strikes me as interesting is how differently we work. While we generally agree on the research question, our approach to research typically bears the imprint of our disciplinary training. Sociologists generally insist on representative sampling to secure scientific credibility. Social workers are particularly sensitive to vulnerability of informants, and hesitate in conducting research with the very frail. As a tribe, anthropologists are probably the most willing to enter into domains that might give other researchers pause.

This may reflect our world view as a discipline in which nothing – data, vulnerability, ethical standards – can be taken for granted as a given.

Looking forward...

As the ERU team and its PIs (anthropologists, economists, and one cultural geographer) embark on our second quarter together, now well entrenched in TRIL research, we are invested in sharing our research findings and perspectives, not only with each other, but working together with the broader TRIL research community. This is a unique opportunity to develop fresh insights and new directions as we draw upon our combined intra-, inter-, and cross-disciplinary perspectives to try improve the lives of elders in Ireland, and elsewhere. These are exciting times, and we look forward to the ongoing challenge.

Athena McLean, editor, and the ERU team



The Social Connection Strand and the ERU Dr. Cormac Sheehan

The first of a series of Data Clinics took place on the 8th of November, 2007, at NUI Galway. The Commerce Faculty Room in St Anthony's was the venue, and from ten in the morning to four in the afternoon the members of the Social Connection Strand (SCS) and the Ethnographic Research Unit (ERU) energetically discussed the initial 'raw' data collected by the ethnographic team.

The data clinic began with the recognition of the interdisciplinary nature of the SCS, with participants from medicine, engineering, anthropology, psychology, and social geography all in attendance. This interdisciplinary mix spurred the examination of the ethnographic data in new directions of research and discussion.

From the outset, there was a general agreement that the Falls, Social Connection and Cognitive Strands are not simply linked administratively under the banner of TRIL, but that Cross Strand work is the future of research within TRIL and especially for the ERU, as represented by the following statement made at the data clinic:

...Everything that happens in the body has an impact on the social life. Cognitive impairment, falls, all that we are dealing with at TRIL, impacts on social connection...

The data clinic was organised around three presentations and group discussion and the last session of the day concerned future research.

Presentations

The first presentation depicted the life of Jane, a well educated woman, who lives alone in a Penthouse Apartment in Dublin. Jane had experienced a 'Falls Cluster', falling three times, outside the home. Jane had a good social network and is active in the voluntary sector. During this presentation reflections were made on the use of space by Jane and the concept of home. Jane also produces maps of

her local area on her personal computer, to prevent her from becoming lost.

Group discussions led to questions concerning the relationship between health and architecture, living space and sociality. The group also was interested in Jane's use of maps and the potential impact on social connection.

The second presentation availed of posters to give insights into the lives of two participants: Cora and Jo. The attendees were divided into groups and allowed to discuss initial impressions, thoughts and possible understandings derived from photographs of Jo and Cora. This proved to be a very illuminating exercise.

Group discussion centered on 'future planning' for Jo and Cora, the importance of routine, spirituality, the concept of being a 'loner', and social isolation. Again the issue of use of space within the home and the local area were of concern, especially the ability to navigate these safely. Specifically to the case of Jo, the relationship between falls, diminishing eyesight and social isolation was highlighted.

The third presentation centered on material from an interview with five women. Using direct quotations and description of the interaction of the five women, their thoughts on a variety of issues, from technology to bereavement were discussed amongst the attendees. The group asked questions concerning friendship, social support, and gender and sociability.

Group Discussion and Future Research

The concept of 'mapping', in terms of social/life worlds and local environs was raised as a potential area for the ERU to study. By doing so it is hoped that the lives of Jane, Jo, Cora, and the five women, would be easy to visualise and therefore fully comprehend their independent and connected social networks.

The ERU was requested to define social isolation, in both a local and Irish context. From

this discussion it was suggested that the ERU should ethnographically validate the Lubben Social Network Scale. This project will begin in March 2008.

Finally, the Social Connection Strand and the ERU discussed the importance of gender, especially in terms of an older person becoming involved in social participation and peer support groups. This is an area which is currently being examined by the ERU.

A special thanks must be afforded to Christine de Larcy for organizing the day, and to Simon Roberts for producing the posters. We look forward to the next data clinic in the spring of 2008.

Above: TRIL researchers at Social Connection data clinic reading each other's thoughts and impressions from photographs presented.

Quotes from Older Men in the ERU Study

"I wouldn't change a single thing about my life or where I live."
A man living with his wife, with all six children living nearby

"I have been constantly depressed since my wife has moved to the nursing home."
Man now living alone.

"See I like my own company." "I'd wake up 5, 6 and get up, no bother, winter, summer. I'd go for a good walk, a good hour," and later to a local pub for "a good dinner." However, a bad bout of shingles and deteriorating eyesight left him isolated and fearful of going out: "I was low for a good six months."
Man describing himself as a loner, but not lonely



ERU at launch of Centre for Excellence in Universal Design

In October 07, the TRIL ethnography team presented a workshop at the official launch and inaugural conference of the Irish National Disability Authority's Centre for Excellence in Universal Design (CEUD www.nda.ie)

The conference involved a number of international leaders in the field of Universal Design and broadly discussed ways of achieving and sustaining a universally designed environment that can be accessed by everyone.

Drawing on the TRIL project's early ethnographic insights, key points were raised and discussed in the workshop, including:

Exploring older persons' attitudes, perceptions and use of technology is critical to promoting universal design that will address their needs.

Such exploration, however, should involve younger generations in order to effectively plan for 'future users'.

Users need to be able to make informed choices, so it is vital that knowledge be shared in clear and accessible ways.

There needs to be ongoing exploration of how technologies for independent living can encompass both assistive technology and universal design principles.

Mary McAleese's Forum on Loneliness and Isolation of Older Men

Eamon O'Shea, ERU co-PI, outlined some of the issues facing older men in Ireland in a recent paper at a forum convened by President Mary McAleese at Aras an Uachtairain. Issues of social integration for older people have been central since the early days of social gerontology. Research in Ireland has confirmed that many of the most significant problems of older people are intrinsically social.

There is a complex relationship between living alone and isolation and similarly between isolation and loneliness which makes generalisation difficult, particularly in relation to their combined effect on physical and mental health. Nonetheless, integration, in all its various forms, is mostly viewed as a positive phenomenon and isolation as a negative phenomenon.

There are 207,00 men aged 65 years and over living in Ireland, the vast majority of whom live in private households. About one quarter of these men live alone. More women live alone than men, but the proportion of men aged 65 years and over living alone in Ireland is the fourth highest in the European Union. The most recent research suggests that about 10 per cent of older people in Ireland have minimal social contact and limited social networks.

A number of elements serve to protect against isolation and loneliness in older age. Social networks, mediated by size, variability and diversity, can protect people against loneliness. Socioeconomic conditions are important determinants of integration and inclusion for older people in the ongoing activities of society. Transport also matters for retaining social contact. Investment, intervention and innovation in these three critical areas would make a significant contribution to alleviating isolation and loneliness among older men and women in Ireland.

