Moving Towards a Three-Way Intersection in Translational Research:
A Sociological Perspective

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I would like to thank the organizers of this summit and all those at Flinders who invited me to come to Australia and, especially, Patricia Mitchell who spent a term at my university in Canada as a visiting scholar. Whenever I told people in Canada that I was going to Australia, they all immediately asked if they could stow away in my suitcases.

My topic this afternoon is translational research from a sociological perspective. I must admit that I was completely unaware of the concept of translational research until I saw the topic of the Research Summit. If I understand what I’ve read in preparation for this talk, translational research often goes, in a sense, from the top down. It takes what has been learned by scientists in basic research, referred to in many publications as “the bench” and translates it into clinical or practical applications, or “the bedside” (National Institute of Health 2006). Ideally, knowledge gained at the bedside should also work its way back up to the scientist.

My guess is that those at the bottom pay more attention to what those at the top say than vice versa. In this case, that means that clinicians pay more attention to what scientists say than scientists pay to what clinicians say. Indeed, a number of sources I checked defined translational research as going only in one direction—from the scientist to the clinic, e.g., Cancer Care Nova Scotia (2006) which defines translational research as: “a relatively new approach that can be broadly defined as applying knowledge gained from basic science to clinically relevant problems,” or the Radiation Medicine Program at the Princess Margaret Hospital at University of Toronto which explains that, “Translational research spans the gap between the laboratory and the clinic. New cancer treatments are often discovered in a laboratory, and an important challenge is to rapidly translate these into treatments that are effective and safe for patients” (Radiation Medicine Program 2006).
Sociologists would refer to this tendency to pay more attention to the perspective of the recognized experts or superordinates as the “hierarchy of credibility” (Becker 1967:241). In any group, people take for granted that those with the highest social status have the right to explain or define the way things are. This belief is so fundamental, that we often are not even aware of this process (sometimes referred to as hegemony). We generally assume that those at the bottom of the social hierarchy function with incomplete information or without the skill or background to interpret the way things are or work correctly. These, usually tacit, assumptions lead us to take more seriously, or consider more legitimate, the definition of reality advanced by the superordinate group or the experts. This hierarchy of credibility exists in all areas of life not just in medicine and health care.

A concrete example to illustrate this concept comes from my own area of research, older people’s, particularly older women’s, experiences of everyday life. Now, think about how we know what we know about old women, in general. The information usually comes from “the experts.” Who are these people? Well, at the top are the doctors. After them come other health-care and social-care professionals—say psychologists, social workers, nurses, occupational therapists, and so on. Then come the family members—ideally a daughter followed by a spouse (who’s probably considered too emotionally involved (and also too old!) to see things “objectively”). Finally, when there’s no one else left, we might ask the older woman, herself, what she’s feeling or thinking about her own situation. She is at the bottom of the hierarchy of credibility.

My guess is that, in terms of health care, this is about where the patient is in the ranking of medical knowledge and care. And, indeed, in the definitions of translational research that I
found, there were no references to knowledge going from the patient or client to either clinicians or scientists. Even the focus on the bedside seems to eliminate learning what we can from people who are healthy or ill.

So, is there a solution? How can we overcome the tendency for those at the top of the hierarchy to define the issues, terms, and solutions to problems, medical or not? There is promise in the development of qualitative research methods to give voice to those whose perspectives are most often absent. Researchers who do this kind of work often write their results in accessible ways so that clinicians, scientists, and policy makers can get an idea of individuals’ lived experience. One of the most vibrant areas of qualitative work today resides in health-related research.

Inductive, qualitative research is powerful in this capacity because it allows the research participants to define what is central and important in their experience. This is in contrast to more deductive, hypothesis-testing style research in which the questions, and therefore, the issues are decided up front based on the opinions of experts or literature which was usually written by experts. I have an example that I would like to share with you that is not directly related to health research but does, I think, express how this works.

This example comes from my research interviewing older widows about their experiences and lives as widows.¹ If you’ve read studies about widowhood, I think you will agree that they tend to be rather dry. They often reduce the most challenging and emotionally taxing transition a woman will endure to a series of correlations that sum up a successful adjustment as well being. Does a widow experience more well-being if she sees her adult children more than once a week, several times a month, or less frequently? This approach reduces an understanding of a widow’s
relationship with her children to a count of how often she sees them. It usually conceptualizes relationships with children in terms of “support” and generally sees only what women need from their children rather than what they might contribute both to members of their family and to the society, in general. It also conceptualizes widows as passive recipients of others’ actions.

In this situation, qualitative research allows us to see the process of negotiation between widows and their children as they redefine their relationship. Instead of asking how often the women saw their children, I asked a question that invited them to tell me what was important in their relationship with their children.\(^2\) I was inspired by the creativity many of the participants in my research used in this negotiation.

Sarah’s strategy, for example, reflects a very refined system of maintaining balance with her children. The basis is a broad, mutual understanding of their not intruding on one another, particularly important because a number of women reported that their children initially became overprotective of them when their husbands died. Sarah also recounted a number of arrangements that rest on a firm foundation of reciprocity that she has established with her children. The following is only one strategy of several that Sarah talked about.

Sarah spends her winters in Florida, which means that she needs someone to pay her local bills and to keep an eye on her house. This can be especially significant in Canada, where the winter temperatures are often well below freezing. Sarah’s daughter pays the bills for her, and her son checks on her house for her. The reciprocity involved is very ingenious:

> Yeah, well, my son is very fond of ice cream, and he can’t get cable [TV] . . . and he loves TV. So I fill the freezer downstairs with ice cream, and I know he’ll be down to watch TV. And he watches the house . . . He checks to make sure that everything’s all right.  \(^3\)
In addition, Sarah’s granddaughter, who attends university:

*If she wants to entertain, she brings the kids down, cooks them supper... So there’s always some, they never know... They never know whether I’m here or not.*

For Sarah, having family members check her house in an unpredictable but reliable fashion is a tremendous benefit.

In addition, most research on widowhood assumes that because widowhood begins when one’s spouse dies, it is only what happens after the death that affects how women experience widowhood. But when I interviewed older widows about their lives, they demonstrated that their experience of widowhood is not contingent only on what had happened since their husbands died but also includes what happened earlier in their lives.

To encourage the participants to frame our interview in their own way, I began with a very broad first question that asked them to tell me about their experience as a widow beginning and ending where they wanted, including or leaving out what they wanted. The very first answer to the first question about being a widow in the first interview communicated the importance of not treating widows as if they suddenly came into existence when their husbands died.

This is what Peg said:

*What was it like to lose him? I suppose, first of all, you have to say what it was like to have him because that would mean that you have... he was a very supportive person.*

*He was quite romantic, in a way. We did our courting during the Blitz, he actually saved my life once in the Blitz at some risk to himself. And then he was overseas, too.*

Peg was not the only woman to take me through a brief history of her marriage and her relationship with her husband. Others, too, summarized their relationships:
We, like, were a couple that . . . he had his interests and I had my interests. Some of them were the same, but we were the type of couple that I would go to a meeting and he didn’t interfere with me going. And when I’d come back, we’d sit in the evenings and talk over what he had done over the day time, and this I miss very much. That’s really the part I miss most of all. (Lydia)

The details of a variety of components have an important impact on what each woman misses, and, in turn, suggests which aspects of her life are most important to rebuild or replace.

Women’s descriptions of their marriage and what their husbands were like let us know what their lives were like as married women. We can begin to see what they have lost. As well, the distinction between marriage and widowhood is not always as obvious as we may think. These women do not find the loss of a spouse by itself to be meaningful. It only makes sense within their own lives when they consider it in terms of what their marriage had been like. It is what and who are missing that matter almost more than what is present. It is this ambiguity that is made visible by letting women tell their own stories in their own way (Faraday and Plummer 1970).

And it is often ambiguity that may be lost or invisible in more traditional, hypothesis-testing research. Unexpected findings may also be a reflection of our misunderstanding or ignoring components of everyday life that people find important. Here, I would like to discuss findings from the Fredericton 80+ Study that is being carried out by colleagues of mine at St. Thomas University. This study has primarily used traditional, quantitative approaches to collect data, but the team also included a life-story component that has helped to explain seemingly contradictory findings in the health component of the research.
As in much health research among older people, the *Fredericton 80+ Study* reports that people’s subjective evaluations of their health are considerably more positive than one would expect from looking at the more objective measures of health. Thus, 89% of the participants in the study reported that they “suffered” from chronic illness and conditions while only 41% evaluated their health as fair or poor. Similarly, when asked whether the statement that they seem to “get sick a little easier than other people,” was true or false, 88% said that the statement was definitely (67%) or mostly (21%) false.

How can we explain this seeming contradiction in findings? We could simply dismiss the subjective evaluations because they do not fit into the valid and reliable scales that we have devised. Fortunately, the team also carried out life-story interviews which help to explain the apparent incongruity in findings. The researchers identified three themes that help explain what is going on: Global Evaluations of Health; Personally Meaningful Activities; and Interpersonal Assessments.

**Global Evaluations**

Global evaluations of health focus on the big picture. So one person said:

*I had a bit of a heart attack in 1982 . . . then in 1990 I had another bit of a heart attack . . . because of the heart problems, I had to have a bypass . . . And they eventually didn’t know what was wrong with me, but [the doctor] come up, and he looked and asked me my history and said, “You’ve contracted Hepatitis C” . . . You’re fatigued beyond control . . . In the meantime, in 1991, I had a herniated disk, and I had a difficult time walking . . .*

So far, this person sounds like he is in terrible health. But then, he concludes by saying, *we’ve*
had our sicknesses, but you know, everything has worked out for the best.

Similarly:

I’ve had three operations. I’ve had my thyroid done and a hysterectomy and another one
. . . When you’re right in it, you don’t think about that too much because you know what
has to be done. . . I had two strokes, they were, what do you call them? Little pieces of
plastic had floated off. I forget. . . . I’ve had problems I won’t even mention . . .

Again, a pretty grim-sounding picture, but then this woman sums up by saying, you have to put
up with it. These global assessments put the health problems of these 80+ individuals into a
perspective that we overlook if we do not allow them to talk about their health in their own ways.

Meaningful Activities

The second theme involves the salience of the ability to carry out activities of significance
to individuals. Their being able to continue with these activities neutralizes their age-related
losses. The following quotation exemplifies this theme:

I’m up and around every day, and I don’t feel too bad. But I’ve got diabetes and angina
and I don’t have high blood pressure because I take a pill for it . . . But I ache, my
shoulders ache. . . . But I can walk pretty good, get around, you know? Climb up in the
cupboard, and things like that. So I guess, for my age, I should be thankful.

Interpersonal Assessments

The last theme that emerged from the analysis of life stories, interpersonal assessments,
suggests that when thinking about their own health, older people compare themselves to others
who are their own age rather than to themselves at a younger age, to an objective measure, or to
concrete indicators of good health. Illustrative comments include:
I’ll be 81 next month, and I’m starting to feel 81. . . . I used to go and walk to the road and then walk down the road for a half mile or so. Now I just walk up to get the mail. That’s about all the physical exercise, and I can’t work at anything very long. . . .

If this man had assessed his health based on himself when he was younger, he would have characterized his health negatively. But he evaluates his own functioning by comparing to others his own age:

The people in my [graduating] class, I got it [a list] and there were 89 names on it–deceased, deceased, deceased–44 of them deceased. . . . You go to your class reunion, and there are only 15 or so of you there, and some of them look a lot worse than I do, I’ll tell ya.

And another:

And then I had a spinal fusion . . . the nerve that runs from your spine down your leg, and my legs used to go numb, and I would have to hold onto something. And the doctor held me off a few years because he said a lot of them, 50%, don’t turn out right. . . . Up at the aquatic centre, there’s 2 people that had the same spinal fusion, and both of them had problems. One fellow has a pain monitor in his back which gives him [medication] . . . But it worked out perfectly for me . . . [I’m in] fairly good health now.

These themes are quite instructive. They tell us that people understand their health in the context of their own lives. This understanding allows people to feel well even when they have age-related problems that seem quite serious and even debilitating from an outside perspective. As Ilder and Kasl (1991 cited in Becker 1994: 72), have noted, “self-rated health has a unique, predictive and thus far inexplicable relationship with mortality.” Their finding should encourage
both clinicians and scientists to pay close heed to what their patients have to say.

The research team sums up the philosophy of their old participants as: “I’m 80; I can do things; you have to accept; and I’m alive.” They suggest that the best way to discover how to measure older adults’ health and well-being is to ask the question, “how are you feeling?”

Another potential contribution of qualitative sociology to translational research comes from the method of participant observation. This method can help us to see people as complex human beings rather than one-dimensional or just bodies as might happen in research. My example comes again from my study of older women’s experiences as widows. As part of my data collection, I helped a widows’ support group host a tea for “seniors” who do not have much opportunity to get out of their homes. This occasion allowed me to see the women when they were not talking to me or to each other about being widows. They joked, laughed, and sang. No one who met them on that day would think about them as grieving, struggling widows. Going to that tea allowed me to see that their lives encompass much, much more than simply being widows. Transcending a single aspect of their lives gave me a much fuller picture than the one I would have gotten if I had only seen them when they were talking about their lives as widows in an interview situation.

I hope these examples entice you to dip into qualitative research that includes accounts of how older people and others participate in and understand their own lives. As the quotations demonstrate, people’s own words are very powerful and, at a minimum, should move the reader to see the old person as a human being with a history and as an active participant in his or her own life. These accounts are both very moving (in fact, a radio interviewer told me she cried through the first 19 pages of my book) and inspiring. If we “translate” nothing else from the
individual person to the clinician or scientist, convincing her or him to see patients, particularly old patients, as human would be a huge accomplishment.

In the end, a two-way street going between the bench and the bedside would be an achievement worth working towards. But if we are to make true progress, we need a three-way intersection where the knowledge of the scientist, the clinician, and the patient or client would meet on equal terms, and where each perspective would receive recognition for its legitimate contribution to our overall knowledge.

Notes


2. Although the wording of questions is not identical in qualitative interviews, the approximate question to elicit this information was: How would you say your relationship with your children has changed since your husband died? 

3. Unless otherwise stated, all quotations are taken verbatim from interview transcripts and all names are pseudonyms.

4. Sharon Kaufman (1984) similarly reports that the old people she interviewed did not find being old to be meaningful, in itself, in their own conceptions of self.

5. The *Fredericton 80+ Study* is a multi-faceted, longitudinal study, funded by the Canadian Institutes of Health Research, that is being carried out by a multi-disciplinary team that includes, doctors, psychologists, sociologists, and gerontologists. The team includes: Stephen Griew, Nancy Higgins, Angela Middleton, Baukje Meidema, Suzanne Prior, William Randall, Marianne Skarborn, Serge Beaulieu, and Theresa Swift. The material in this discussion is based on Prior and Miedema (2005) as well as on material reported by the research team to research participants in Fredericton, NB on November 8, 2006.

6. Note that there really is no such thing as an “objective measure.” These scales and questions reflect an understanding of being healthy that has been developed by the experts with an undue emphasis on biomedical definitions.

References


Prior, Suzanne & Baukje Miedema 2005. “Healthy as a Horse?”: The incongruence of subjective and objective health evaluations. A Poster presented to the Canadian Association on Gerontology Scientific and Educational Meeting, Halifax, NS, October.
