PIVOTAL MOMENTS

A Retrospect on Key Events/Moments 1980-2021: Notes From a Retirement (almost) Presentation, 2021

COVID restrictions prohibited the usual "retirement address" and downsized it to an outside show & tell event.

In 1977 I loaded the kids in the car, tied the kids bikes onto the back of the car, and drove for 2 days down Interstate 80, from Central Pennsylvania to Salt Lake City. I was one of 4 students m Madeleine Leininger's cohort of doctoral students. Our first informal as the 2nd cohort in the PhD program, was an outing to the Utah State Fair, where we, all 4 new students, bought a sign that read:

Nothing in the world will take the place of persistence. Talent will not. The world is full of unsuccessful people with talent. Education will not. The world is full of educated derelicts. Genius will not. Unrewarded genius is almost a proverb. Persistence and determination alone are omnipotent. -Calvin Coolidge

Dissertations in Fiji (1980-81)

Background: Enrolled in two PhD programs simultaneously (Nursing and Anthropology) with two dissertations to complete seemed an insurmountable problem. I selected two related topics, with fieldwork in Fiji:

 Cultural response to the pain of parturition in Fijian and the Fiji-Indian cultures (Nursing), and



Pulse Wave Velocity Computer – to measure pulse transit time. Circa 1981

(2) The health effects of infant feeding in the neonate In the Fijian and the Fiji-Indian cultures (Anthropology).

I had visited Fiji previously as a tourist and knew that Fiji's population was approximately 50% Fijian (Melanesian/Polynesian) and 50% East Indians brought to Fiji (1880-1920) as indentured workers for the sugar cane. Thus, this population provided a "naturalistic laboratory" for comparative studies.

Study 1

I thought the trick for this comparative study, was the *measurement of childbirth pain* and purchased a pulse wave transit time (PTT) machine, battery powered & small enough to fit in a backpack. This measure of pain was to be used with physiological measures as labor progressed. BUT the PTT machine broke very soon after arrival in Fiji, and I realized that if I was to complete this dissertation, I would have to move to a study that primarily used qualitative, ethnographic methods.

I now realize that the measurement of pain physiologically was inappropriate. [Remember Jan—all the easy research has been done]. We know what is painful about childbirth— measuring it would be quantitative thinking. And would not necessarily answer my research question. It would have derailed the research.



<u>Pivotal Moment #1</u>: The Appreciation of Qualitative Inquiry. Without a skill set in qualitative methods, I would have been s.t.u.c.k. and "up the creek without a paddle". I realized that Methods formed a toolbox, opening vistas.



Breaking this machine saved me from Terminal embarrassment.

Study 2.

My proposed study to compare how mothers' breast and bottle fed infants, in rural areas (Suva) with infants in transitional area (Vanua Levuand the "unacculturated" outer islands (Lau group), but this study was denied by the Minister of Health. I redesigned the study to compare the infant feeding of infants, birth to 6 weeks on the main Island (Viti Levu), with mothers from Fijian and Fiji-Indian cultures. Data were obtained from hospital charts and postnatal records, and analyzed using path analysis, and supplemented with semi-structured interviews conducted with a subset of mothers in the postnatal clinic.

In retrospect, this was a much more manageable project, doctoral dissertation-size.



Pivotal Moment #2: Appreciating Mixed-methods Designs. *Much* later I realized that my nursing dissertation was a Qualitatively-driven mixed-method design, and my anthropology study was a Quantitatively-driven Mixed-method design. This insight formed the basis of my conceptualization of mixed-method designs.

Associate Professor and Clinical Nurse Researcher (CNR), University of Alberta (1981-91)

My first assignment as CNR was to "investigate" patient falls on the women's rheumatology unit. "Only 35 patients?" said Bob Morse. "It will take you 32 years to get enough data". So I



Searching for solutions for care without restraints. (i) Bed alarm; (ii) bed alarm positioned beneath mattress; Circa 1984. (iii) Prototype of low bed, 1:18, Circa 1996.

expanded my population to include all patients in the medical center, the nursing home, and the rehabilitation hospital. The resulting Morse Fall Scale (See report on Patient Fall Research, this site) was finished in 1986 was awkwardly accurate. Knowing who was likely to fall and not knowing how to prevent the fall, meant that falls nurses would "tie patients up" in increasing

numbers. We delayed publication of the scale until 1991, and from the mid 80s explored ways to provide safe care without restrains. We developed a bed alarm



from blood pressure cuff and an air pressure switch and obtained a patent for a low bed. We also conducted a study using 24hr surveillance videos to document the behavioral effects of releasing restraints. (Yes, backwards! It is not ethical to study the effects of *applying* restraints!). This "fall" research is continuing 35 years later, now focusing on the biomechanics of bed egress, targeting bed height and safe room design.

Pivotal Moment #3: Nothing is as easy as it seems.

1. The concealment of clinical data by health care systems, and the refusal of institutions to provide access to clinical researchers to "sensitive" data, impedes the development of therapeutic interventions.

2. We still know very little about fall trajectories from the patient's bed or patient's room—it is easier to look at (and show) the moonscape or now, see the end of the universe.

<u>Pivotal Moment #4:</u> Take a break. Do something else. But keep on researching.

The Psoriasis Research Project (with David Young, PI)

At the request of the woodland Cree medicine, we investigated the efficacy of traditional treatment of psoriasis. Treatments consisted of herbal tonics, and lotions for the lesions and traditional ceremonies, including

sweat lodge ceremonies. I learned the hard way about "competing paradigms" when the Alberta Dermatological Association wrote the University chastising them for funding a project that was wasting grant funding. Fortunately, the University continued to support the project.



Focusing on Nursing Research (1984-1990)

At this time, there was no PhD Nursing program in Canada, but I had many funded master's students, all doing clinical nursing research. Most did grounded theory, but some ethnography and ethnology. We were "housed" in a rather large space, (our "lab"), so that all students were together, all knew each other's topics, methods, successes, and what was not working so well. This was a fantastic way to learn qualitative inquiry: All students published their projects as journal articles, and a collection of these studies was also published as a book "The Illness Experience: Dimensions of suffering" (co-edited with Joy Johnson). Further, I was teaching qualitive methods, and learned the value of publishing, disseminating both articles and texts. My first methods text was with Peggy Ann Field, in 1985, and this was followed quickly with a few edited books describing qualitative methods

Following from my infant feeding study in Fiji, we conducted several studies on breast feeding in Canada, including several previously "unexplored" topics: mothers' leaking breasts, learning to express, how working mothers manage lactation, patterns of weaning, and minimal breast feeding.

<u>Pivotal Moment #5:</u> Learning to grasp the bigger picture

"What's Your Research Program?"

My Dean, Marnie Wood called me in one day and asked: "What's your research program?" Thinking on my feet, I said "Comfort". "What is it?" she asked. "I don't know", I said. "Find out" she said. So, I applied to NINR (National Institute for Nursing Research) for a 3-year foreign award and was successful. With a 5-year renewal after my move to Penn State, this led to a large volume of work on suffering (those in need of comforting) and comforting strategies in many clinical areas of nursing. It led to the deconstruction and delineation of many concepts in nursing and mid-range theories of suffering, enduring, and comforting. The research team explored caring, commiseration, compassion, sympathy, empathy and compathy. And later concept essential to nursing relationship: Hope, trust, socials support, normalization. We worked with many groups of patients and nurses, trauma care, NICU, rehabilitation, bereavement.

<u>Pivotal Moment #6:</u> Swimming upstream: Hard yet a Necessary Stepping-stones.

Concept development: Foundational Inquiry (1990-1996)

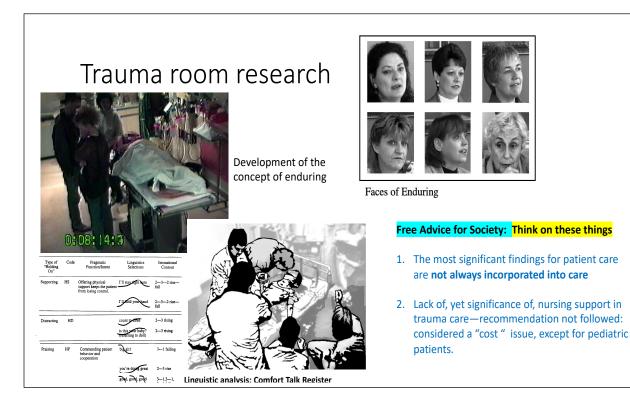
In the process of exploring concepts, we realized we were working on the edge, developing methods as we analyzed data. Often our articles were rejected: One reviewer from ANS (*Advances in Nursing Science*) wrote: "If we do not teach Avant & Walker, then what do we teach?"

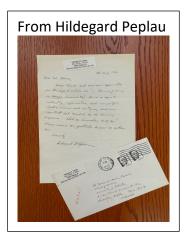
Yet some did read our articles. On April 29th, 1997, Imogene King wrote: "I always wondered why most doctoral programs taught doctoral student Wilson methods "only". I also wondered why there is some confusion about concept development and concept analysis. My question has been 'How can students analyze concepts if they don't know who to develop them.'" This research program was often difficult, and often upset mainstream theorists. Yet these articles were all later published, but there were rewards, including a letter from Hildegarde Peplau, following our publication deconstructing caring.

Suffering and comforting: Trauma Care. (1991-2000) The Pennsylvania State University.

The most difficult project I tackled at this time was exploring the ways the nurses provided comfort to patients who were in state of acute distress—agony—primarily using video data. We identified and documented the way nurses talked patients through, and used touch; we included relatives' distress, identified behavioral indices of suffering states, and developed midrange theories of suffering, enduring and the resolution/outcomes of suffering.

Obtaining the necessary consent from everyone who entered the trauma room, from all patients and relatives was difficult, but possible, and the co-operation and support of staff was overwhelming. Collecting data around the clock required a large team and I am grateful for the funding received from the US National Institute of Nursing Research. The feasibility of such





research is dependent on the interpersonal skills, the astute observational skills, and the research and clinical knowledge of the research team. Relationships must be earned with the clinical nursing staff, and the medical staff, and the administrative team must consider the work of such a project. Family members and patients are the most supportive, and quickly see and understand the worth of such research.

As method in clinical and mixed methods become more commonplace, and as project become larger in scope and complexity, team research is becoming the norm. And such teams may make or break the project. I have been so lucky Thank you.

Publications from this project were numerous, and significant, but the strategies for care identified—and the personnel necessary to provide such essential care have not



been adopted or implemented, certainly in a significant way. The trauma setting and the lack of standardization in patient trauma and care requirements appear to inhibit any form of clinical trial.

Team research may be productive, but all members of the team must be invested, communicate and "on the same page".

To achieve this, the team must have

- Shared space
- Be in that space
- Be invested—believe in the worth of the project
- Be fully knowledgeable about all phases of the project.
- Respect qualitative methods

<u>Pivotal Moment #7:</u> Support for Dissemination of Qualitative Methods is Possible.

I thought that teaching qualitative methods was an impossible dream. I envisioned a training center, modelled after the Hastings Center for Ethics that was then housed on the campus of

Pace University Pleasantville, NY. The Hastings Center had several components I considered essential: National presence, newsletter, space for workshops provide leadership and instruction. But most of all funding. At this time, qualitive methods was primarily taught by mentoring on research projects, and in few disciplines-primarily anthropology and later in the 90s in education and nursing (by the nurse anthropologists). There remained a stigma attached to qualitative inquiry, so that few doctoral programs offered courses; and it was difficult to get qualitative inquiry published (although QHR was launched inn 1991).

Dissemination of Qualitative Research Methods (1997-2007) University of

Alberta

Then, a miracle happened. The University of Alberta offered me a position, space, assisted with funding to furnish the space, and we were awarded a 3-year establishment grant from the Alberta Foundation for Medical Research.

Bottom line: Pivotal insights & More Free Societal Advice



A. Its really true: Substantive research contributions do not come to "fruition" until 15 years after first publication—paradoxically after the articles have "expired" and are not included in library searches.

B. Ironically: As measured by publication metrics, development of methods is most "fruitful." But remember <u>methods are least supported by university role and federal grants.</u>

C. <u>BUT</u> the major recognitions (as measured by publication metrics) are awarded for methods, not social science breakthroughs. Methods have a large utilization base and are championed through books and articles. Citations occur casually, and often without effort on the part of the cite-er.

On the other hand, Clinical breakthroughs require policy change, by-in from faculty and incorporation into the basic texts before they become accepted as standard practice. For this reason clinical research must be conducted with the researcher's having "real" clinical appointments and clinical by-in to their research programs. HOW?

The Development of the

International Institute of Qualitative Methods (IIQM)

The IIQM opened in February 1997, with tis structure and some programs ready in place. The administrative structure consisted of 5 main administrative sights-an international web extending from the Main University of Alberta site. These international sites (hubs) were:

- Asia (led by Kyung Rim Shin, Korea)
- Oceania (Led by Irena Madjar, Australia)
- Europe (Led by Mieiki Grypdonck, Belgium/Netherlands)
- Middle East (led by Lea Kacen, Israel)
- Africa (led by Marie Poggenpoel & Chris Myburgh (South Africa)
- North American (The IIQM, Janice Morse).

Additional International hubs were added in 1999

• Mexico/Ibero-America (Led by Francisco Mercado Martinez)

Later:

- UK (Led by Immy Hollaway)
- South America (Led by Margareth Angelo, Dulce Maria Rosa Gualda

& Eneas de Carvalho Aguiar)

Each of these International sites worked as a hub to support university sites in their region, and created their own programs including workshops, regional conferences and even journals in their own languages.

Th IIQM model was extraordinarily successful and by 2006 we had 115 universities formally linked by a memorandum of understanding to the IQM. A complete listing of the programs from 1999 to 2006 please turn to this section this website.

Two formal conventions were held each year: one supporting *Qualitative Health Research;* and *the other The Development of qualitative methods.* The International sites rotated hosting the International one in their region, and the other was held in Canada, often and the Banff Center, in the Canadian Rockies.

Other programs were extensive: The University of Alberta site, hosted international visitors; offered workshops, including week-long sessions, *Thinking Qualitatively*, every summer. We hosted lunch-time seminars and provided research consultation. We had a cluster of doctoral students, including walk-ins seeking advice, and visiting professors. Our funded research consisted of 2 projects funded by CIHR: (1) Estimating the risks inherent in qualitative interviews, and (2) a training program *EQUIPP (Enhancing Qualitative Understanding of Illness processes and prevention).* We had a hoard of doctoral students, including walk-ins seeking advice; visiting professors.

This was the first such institute internationally, and now 20 years later, qualitative courses have become standard in graduate programs, there are many journals accepting qualitative manuscripts, and such institutes are becoming common in Universities or as component of their methodology centers.



In 2007, 10 years after its inception, Norm Denzin created another institute, International Congress of Qualitative Inquiry, at the University of Illinois, Champaign, modeled after the IIQM.

Mission for the development of qualitative inquiry completed? I accepted a position at the

University of Utah to continue falls research based on biomechanical fall risks. The IIQM continues from the University of Alberta. See its website, <u>https://www.ualberta.ca/international-institute-for-</u> gualitative-methodology/index.html



However, to continue with the dissemination of qualitative health research internationally, the Global Congress for Qualitative Health research was formed. This organization is now led by Seung Eun Chung, Korea (https://www.gcqhr.org/).

Introducing the First Global Congress for Qualitative Health Research: What Are We? What Will We Do—and Why?

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<u>Pivotal Moment #8:</u> Right! In retrospect, "Persistence and determination alone are Omnipotent."

After 15 years at the University of Utah, we are closer to understanding the effects of frailty and impaired balance on patient falls, but still are perfecting a safer hospital room. So, now retired, I keep writing, hoping those with the power to affect changes are reading, changing policy, and building codes, administrating fall risk, and patient care, and nurses keep thinking, even reading "old stuff, and providing patient-centered care...

Jamie M. Mare, 2022

