Professor Tina Koch

Leverhulme Public Lecture

Tina Koch's story

My story began in Arnhem, the Netherlands. With my family, I migrated to Australia when aged nine. In 1967 I became a registered general nurse, graduating from the Royal Adelaide Hospital in South Australia (SA). I have Bachelor of Arts degree majoring in sociology and English from Flinders University of SA (1983) and a PhD in Nursing from the University of Manchester, United Kingdom (1993). I have held positions as Professor of Nursing at Flinders (SA) and Newcastle (NWS) universities in Australia. Researching alongside participants or in collaboration with participants has been my strong methodological preference. I have developed a research programme driven by participatory action research

Why select Participatory Action Research (PAR)?

Because it allows you to research alongside or *with* participants to stimulate action, reform or change 'anything' e.g. individual and/or group development, improve practice, inform policy, remodel or restructure an organisation / institution.

The PAR approach has been around for decades and has been shown to work well in community development

Practical relevance

PAR is motivated by a desire to secure authentic information *with* & about people and their situations that is meaningful & useful. The main aim is to involve participants in every phase of the research process. Participants are facilitated to contribute their experiences and ideas, make plans and partake in effective reform and/or action. Precisely because participants drive the agenda and take ownership of the study and its outcomes, this research has practical relevance as reforms initiated by participants are often sustainable.

Overview of my Participatory Action Research (PAR) Studies

- Over 40 PAR studies were funded & completed
- Participants (over 300) have driven the research process to explore situations pertinent in their lives
- Participants were indigenous Australians, adolescents, older people, people from diverse ethnic groups, gender specific groups & families.
- Majority were community dwelling participants living with a chronic illness / condition
- Participants & researchers explored sensitive topics: sexuality, abuse, disturbed mental health

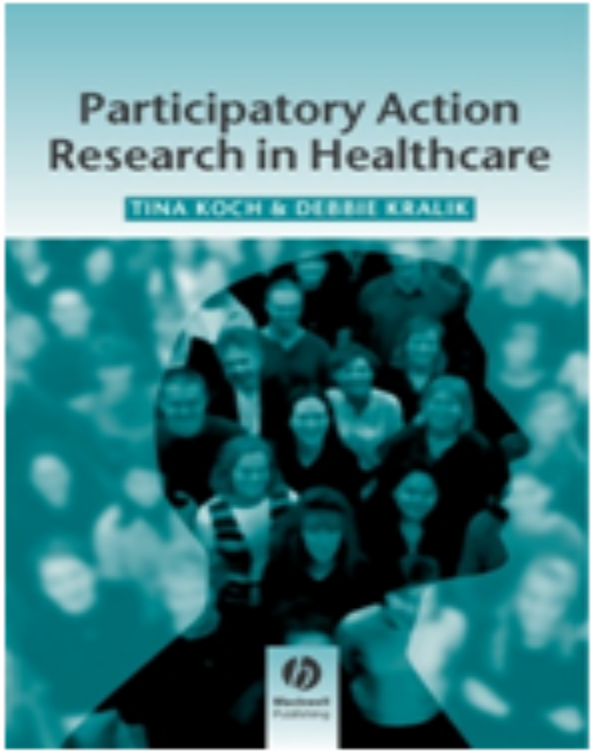
Research programme driven by PAR

A programme of research was developed in the area of chronic illness experience, with a theoretical focus on transition, or the way in which people learn to take the consequences of chronic conditions into their lives and move on. This research programme was driven by PAR. Outcomes include numerous publications: 80 plus articles in refereed journals, 12 book chapters and several books including a participatory action research text book published by Blackwell.

Koch & Kralik (2006) Text Book

Participatory Action Research in Health Care 2006

- Examines the ways in which research can inform health-care practice
- Includes guidelines for practitioners on implementing participatory action research
- Includes issues related to different disciplines within the multidisciplinary team
- Explores the benefits for community development and health promotion
- Uses exemplars from practice



Storytelling: a distinctive aspect of Koch & Kralik's PAR approach

There are many versions of PAR. The distinctive aspect of the Koch and Kralik's (2006) participatory action research is a **story telling** component which usually occurs when the participant is asked to tell her/his story either in one to one interview sessions and/or within the PAR group process.

Story, narrative and PAR

Storytelling: The term 'narrative' is synonymous with 'story' . Observe three nested uses (Riesmann 2008):

- The practice of storytelling: stories told by participants
- Narrative data: empirical materials & interpretative accounts developed by interviewer (a story about stories)
- Narrative analysis: the systematic study of narrative data

PAR process: Transcribed stories are treated analytically as units and so maintain their storyline rather than fragmented into thematic categories. The story is given structure by the **look, think** and **act** framework. The shaping of the story, the analysis of the narration and its editing is done in collaboration *with* participants.

Participatory Action Research

Participatory

- In collaboration ***with*** participants
- Participants ***determine*** the agenda
- Participants ***drive*** the research
- Participants *decide* on actions

Participatory Action Research

Action /movement toward change/reform

- **Capacity** building
- Building on **strengths**
- Changes are **initiated** by participants
- **Pace** for change is decided by participants
- Outcomes are **actions** (individual growth and/or community development) **reform**

Participatory Action Research

Is it really research?

- PAR follows an established research process trajectory: research question, aims, objectives, literature review, systematic data generation and analysis, 'findings', report & publications.
- And building up of study 'findings' can lead to the development of theory e.g. Kralik's transition thesis.

I repeat, my argument is that an PAR apprenticeship is required to learn the PAR processes. These research skills cannot be learned from a text book. Two studies will be discussed to show the apprenticeship model.

- **(1) Older patients: Prevention of Delirium in the Acute Care Hospital setting**
- **(2) What can be done to improve maternal health in Papua New Guinea PNG?**

Older patients: Prevention of Delirium in the Acute Care Hospital setting

Title: Practice redesign and partnership *with* clinicians to improve quality of delirium care for older people (2007)

Study: Practice redesign and partnership *with* clinicians to improve quality of delirium care for older people (2007)

PAR Apprentices: Jenny Day (Project Manager) and Isabel Higgins

Chief investigator: Tina Koch

Context: Delirium & older people

Delirium is characterised by a disturbance of consciousness and a change in cognition that develops over a short period of time. The disorder has a tendency to fluctuate during the course of the day.

Delirium is a high-order failure of a complex system and may be seen as the body's response to noxious insults which the frail older person cannot tolerate e.g. medications, infection, dehydration, temperature change (Rockwood 2002)

Delirium is common in hospital

Delirium is a common problem affecting up to 56% of older people admitted to hospital.

Up to two thirds of cases are not recognised (Inouye et al, 2001). Hypoactive delirium is less well identified (Meagher, 2006) and yet more frequent than the hyperactive type.

Even when symptoms are recognised they are often misidentified and mistreated.

Delirium is associated with increased length of stay and often results in discharge to long-term care.

Delirium is rarely caused by a single factor and represents one of the most common potentially **preventable adverse events** for hospitalised older persons.

Why redesign practice?

- Under utilization of evidence (research findings)
- Multiple practice guidelines but very few are implemented and evaluated in patient care
- Education and in-service programs are provided but have they really made a difference to practice?
- Practice change is often imposed rather than a result of collaboration *with* clinicians

Commitment

- The key to PAR groups successfully making changes to practice is the involvement and commitment of administrators who sanction, support and promote every aspect of the research process
- This meant that organisational structures, contract agreements and communication strategies needed to be negotiated and be in place at the commencement of the study
- Allocated rostered time for participant clinicians to attend one hour PAR groups for six months of the study

Pilot study in an acute hospital medical ward Feb to July 2007

Research Team

- Jenny Day (project manager) apprentice
- Dr Isabel Higgins apprentice
- Professor Tina Koch (chief Investigator)
- **High Speed Typist**

Participant clinicians (recruited as volunteers)

- 7 nurses, 1 physiotherapist

Oversight Committee

- Professor Dimity Pond (GP Practice)
- Professor Kichu Nair (Geriatrician)
- Professor Michael Hazelton (Mental Health)
- Dr Ashley Kable (Quality Improvement)

The pilot study

The overall aim is to use a partnership approach through the use of participatory action research processes to redesign the implementation and evaluation of best practice guidelines for prevention, early detection and management of delirium in older people in an acute care setting (one ward)

Objectives

Establish a participant action research (PAR) group in the designated acute care setting and collaboratively redesign practice.

Literature review: What is the evidence for best practice?

Researchers completed a literature search of the delirium literature (2002-2007).

111 research papers were reviewed. Excluded from review were deliriums related to a surgical event, intensive care, palliation or as a result of medication or alcohol withdrawal.

Three major research bodies were identified

Delirium Guidelines

Seven published guidelines including APA, Cochrane, CNC (NSW) 2006.

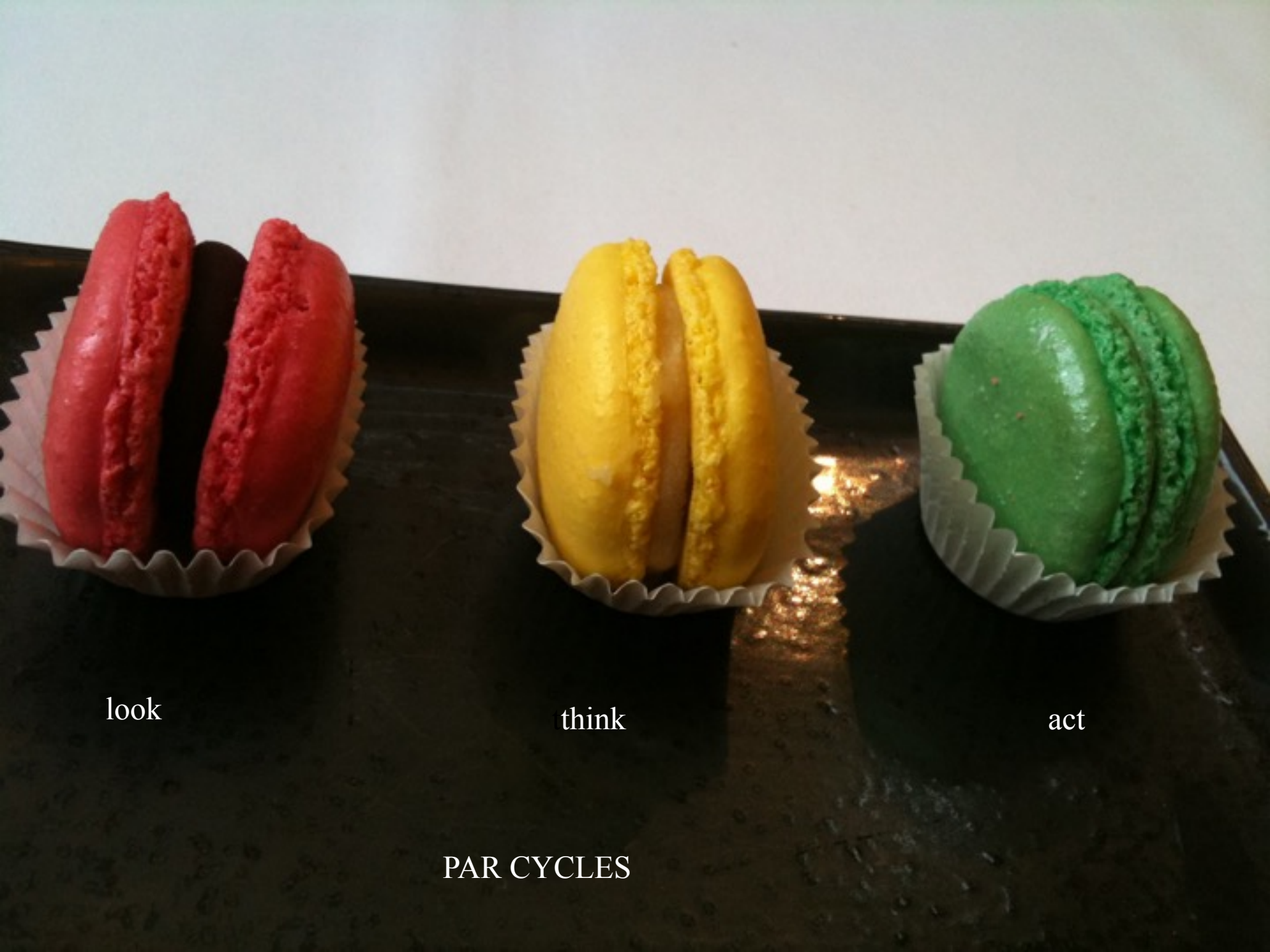
Selected were:

UK National Guidelines (Royal College of Physicians and British Geriatrics Society) 2006 *The prevention, diagnosis and management of delirium in older people.*

Researching collaboratively

Three researchers (Day, Higgins & Koch) met with eight (8) health care professionals for 14 PAR group sessions.

Participatory action research is a process where 'we', researchers and participants, systematically *work together* in cycles of ***looking***, ***thinking*** *and* ***acting***, explore ways in which we can improve practice



PAR CYCLES

PAR Process

Look: Each participant was invited to talk about an experience with delirium. Stories were transcribed verbatim and returned to participants to following week with analysis against the UK best practice guidelines

Think: Thinking was stimulated when participants received condensed feedback from the previous PAR session and were facilitated to reflect, interpret and explain practice.

Act: The agenda was driven by participants. The PAR group decided on actions to improve practice.

Storytelling

A clinician recalls her first experience when looking after a patient with delirium, thereafter each clinician talks about an episode where the care recipient has become delirious during the hospital stay. These stories are recorded, analysed and returned to the group.

Hyperactive delirium

Storytelling: Common events

Ten (10) of the generated stories were about an event where a patient was in a highly agitated, frantic mood. Delirium was detected only when it had reached crisis stage, and identified only because the behaviour of the patient could not be ignored.

We asked: What about patients with hypoactive delirium, were they missed? Clinicians more easily recognised the agitated restless patient with delirium and overlook the older person who is “quietly delirious, sitting listless and unnoticed”

Seven data sources

1. Stories told by participant clinicians (analyzed against guidelines)
2. PAR group data (14 sessions with verbatim transcriptions & analysis)
3. Researcher journal analyzed (**reflections**)
4. Post PAR research team debrief observations & analysis with particular interest (**group dynamics**)
5. Chart audit of 37 discharged patients
6. Observation of multidisciplinary 0900 hours case management meetings
7. Observation of nursing staff handover

The 5th PAR group session: a clinician talks

- Helen: The common thread through all that is that there is a lack of understanding of delirium in this ward. Perhaps there should be a place for a protocol that we are all trained in. It doesn't have to be pages and pages, but a simplified document that we can look at down in point form so that that is a starting point; we can look at that person and try and make a clinical assessment as to whether that patient is delirious or not... it's the older patient that the literature seems to feel is more at risk.

Research team debrief after each PAR group meeting. One example

- Jenny: Helen, I saw her sitting back, but I'm wondering if we followed what she suggested or did we go against it...
- Isabel: So the point that you're making with Helen is that we…
- Tina: I just wanted to make sure that I honoured her suggestion; we both built on Greg's, but did we build enough on Helen ?
- Jenny: Their suggestions for practice redesign are quite different.

Action: Awareness raising

- The PAR group *eventually* **agreed** that all patients were at risk of delirium and whilst the ward's focus had been on 'urgent' management in response to a patient's agitation, it was timely to shift **to prevention and early detection**

- Participant clinicians **decided** to develop a delirium alert protocol. This laminated protocol was to be inserted in all bedside patient charts.

- Participants as champions **agreed to introduce** the protocol (role model and education) within the ward

ACTION
Development of delirium alert protocol

Adapted an intervention protocol to address delirium risk factors publicised as the Hospital Elder Life Program (Inouye et al, 2000).

This is a standardised protocol for the management of six delirium risk factors; (1) cognitive impairment, (2) sleep deprivation, (3) immobility, (4) dehydration, (5) vision impairment and (6) hearing impairment

ACTION

Development of delirium alert protocol

This laminated one page protocol was inserted in a folder at the end of the bed of every older patient admitted to this acute care setting ward. Staff were reminded to read the standardised protocol alonf side the temparature charts and medications. The physica presence of the chart (see next slide) served to increase the awareness of staff to delirium risk factors: (1) cognitive impairment, (2) sleep deprivation, (3) immobility, (4) dehydration, (5) vision impairment and (6) hearing impairment.

Look, listen, link, think and act

Look for & think "delirium"
"IFACT"

Inattention
Fluctuating cognition
Acute change in cognition
Changed level of consciousness –
o hyperactive – loud & aggressive
o hypoactive – quiet & subdued
o mixed
Thinking is disorganised

Look for risk factors of delirium
"CDIVAS"

Cognitive impairment
Dehydration
Immobility
Visual impairment
Auditory impairment
Sleep deprivation

Findings: Where have all the 'deliriums' gone? Clinicians talk…

- We are starting to link it up
- We are not getting as many deliriums so we are getting 'on top of it' & 'catching it earlier
- This is weird we are not getting so many deliriums. It is seasonal? No it is just that we are picking it up earlier
- Delirium is on the agenda. The D word is used. The D word is being spoken out loud
- Students are picking up on it. They are taking photocopies of the protocol
- It actually makes me think about clinical practice

‘We are on to it a lot earlier now’

Several months later a clinician said: ‘We had one female patient about to be transferred to a Private hospital. She was perfect, but overnight, there was some confusion. Nurses picked it up straight away. I asked to keep her for 24 hours, saying that I think she has some delirium. Before we brought it to the attention of medical staff, we had checked the bowels & the urine and then we ask the medical team to check the bloods. ‘What is going on with their creatinine?’ Some of the medications are an issue so they are reviewed. In this case the nurses had already done a urine test (MSSU) and waited for the medical team to assess. One statum dose gentamycin was given and the next day she was perfect. In the past we would have probably let that go, wait until we see urine and then start the treatment. We are on to it a lot earlier now’.

From Chaos to Calm

- Verbal ‘ward’ handover (delirium is now discussed)
- Written communication has changed
- No physical constraints have been used in the last three months.
- No documentation (no forms to complete)
- There is no need to write a comprehensive patient management plan as early detection has prevented escalation into acute hyperactive delirium
- Workload has decreased
- No need to recruit additional staff
- Staff have claimed **ownership** of the delirium alert protocol (it is in their language)
- The protocol makes sense to practice (relevance)

Publications

- Day Jenny, Higgins Isabel and Koch Tina 2009 Delirium and Older People: What are the constraints to best practice in acute care? *Journal of International Studies* Volume 3 Issue 3 Pages 170-177
- Day Jenny, Isabel Higgins, Tina Koch 2009 The process of practice redesign in delirium care for hospitalised older people: A participatory action research study *The International Journal of Nursing Studies* Volume 46 Issue 1 pages 13-22
- Day Jenny, Isabel Higgins, Tina Koch 2009 Delirium and Older People in Acute Care in *Interdisciplinary care of older people: Issues and innovations* Chapter 15 Pages 252-269 Editors Nay & Garratt March 2009

Nina Pangiau PhD candidate

What can be done to improve maternal health in Papua New Guinea?

THE UNIVERSITY OF NEWCASTLE
AUSTRALIA

Nina Pangiau PhD candidate

What can be done to improve maternal health in Papua New Guinea (PNG)?

Supervisors:
Tina Koch & Isabel Higgins

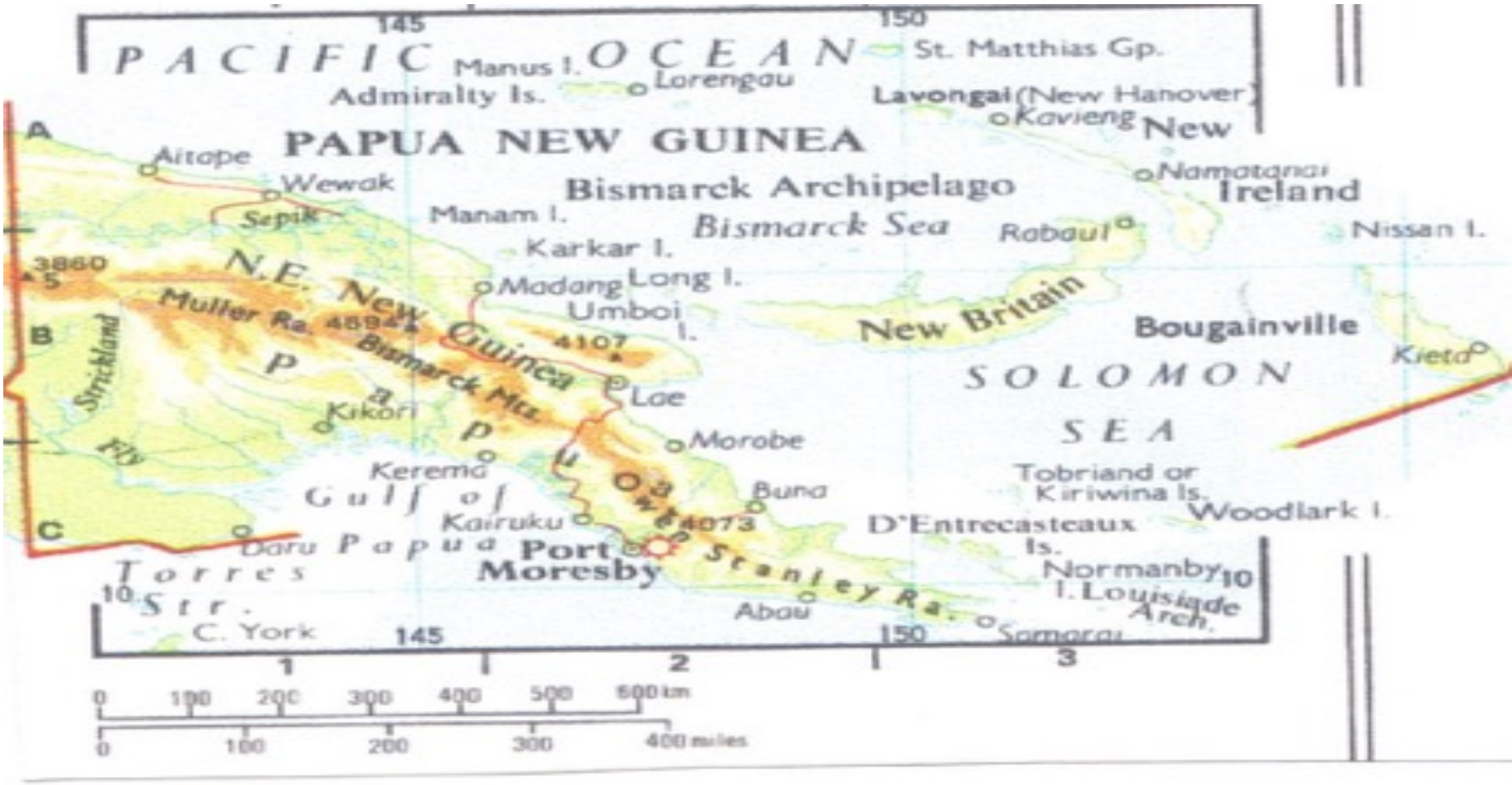
Apprenticeship Phase

Objectives

1. With 4 PNG women living in Newcastle collaboratively explore ways to promote maternal health *with* individual women initially (one to one interviews) and then collaboratively with the group (participatory action research)
2. Apprenticeship & practice PAR data generation 'look, **think** and act', concurrent analysis, feedback cycles, facilitating and managing PAR group dynamics toward **action,** and writing up this chapter.

   Considering what has been learned (objectives 1 & 2) identify success and constraint indicators in using PAR as a community development strategy in her PNG village

Papua New Guinea New Ireland



Nina's PhD PAR Structure

Chapter 1 Introduction
Chapter 2 Context: global & local
Chapter 3 Literature review
Chapter 4 Philosophy underpinning PAR methodology
Chapter 5 The PAR research process, ethics and rigour
Chapter 6 Phase 1 Apprenticeship in PAR Newcastle
Chapter 7 Phase 2 Storytelling with local women PNG
Chapter 8 Phase 2 PAR groups Lomakunauru village
Chapter 9 Phase 3 Reform outcomes/Millennium Goals
Chapter 10 The thesis is that ... Objectives met ... The research question has been answered ...

Context

The public health parameter that shows the widest discrepancy between developed and resource poor countries is the maternal mortality ratio (MMR). This is the number of women who die (per year) from pregnancy-related causes per 100,000 live births.

Context

In sub-Saharan Africa one in every 16 women dies in childbirth. In the UK, the comparable ratio is one dead woman in every 8,200. Maternal mortality is the most dramatic health inequality. There is evidence that maternal mortality rate can be dramatically reduced. Thailand cut it by 75% in 18 years; the Matlab region of Bangladesh cut it by two-thirds in 21 years. Yet in 20 years, the rate in sub-Saharan Africa has barely budged. The lamentable lack of progress on Millennium Development goal five - a 75% cut in the maternal mortality rate by 2015, to which 189 countries have committed themselves - has become an acute embarrassment to the world. After Afghanistan, PNG has the largest MM in the world.

Context

Papua New Guinea 700- 900/100,000

Australia & United Kingdom 7-8/100,000

This figure means that a young woman in PNG has to consider that her lifetime risk of dying from a pregnancy-related cause is about one in 20, whereas the lifetime risk of an Australian /UK woman dying from a pregnancy-related cause is probably about one in 10,000 (Mora 2009)

Ninas Rationale for selection of PAR

- Story telling & oral tradition
- Literacy level of PNG village women (45%)
- Empowering as actions/reform/change will be driven by women themselves
- Ownership of reform actions
- **Sustainability** of changes instigated

PAR Apprenticeship Phase 1

Participants (4 women)

Mary, Gloria, Silly and Faye

Fictional names

Research Team

Nina Pangiau (PhD candidate)

Supervisors

Profs Isabel Higgins & Tina Koch

The proposal was approved by the University's Ethics Committee

One to one interviews

- Story telling: ‘tell me your story of pregnancy & birthing’- just one story
- Language selected
- Transcription verbatim
- Traffic lights analysis framework: **look, think, act & strengths**
- **Feedback**
- **Reflection**
- Evaluation

Supervision one to one interview

As discussed. the distinctive aspect of the Koch and Kralik (2006) adaptation of PAR is a story telling component .

Nina interviewed Mary under the supervision of Professor Isabel Higgins

Mary is from Papua New Guinea (PNG) and a student at the University of Newcastle. She volunteered to participate in Nina's PhD apprenticeship in learning PAR.

Mary's story introduction

Mary is now 37, a single parent who has been living on her own for 13 years. She has had three children all born in PNG

In Nina's first interview with Mary she tells this story: a birth story with her first born in the late 1990s. Her pregnancy occurred when she was very young and still in high school. Her son's father came from another village.

Nina asked: 'Mary tell me about birthing one of your children in PNG'.

Mary's story 1

My parents did not accept the pregnancy. That meant I could not go home to deliver and be with my parents. I was with my husband's (people) in his village. That is in East Sepik in the Passam area. If I were living with my parents, they would respect me and they would give me the best food and expect me to rest as much as possible because I am pregnant. Living with my husband's family meant I had to work to make them happy. You can gain their respect only through working hard. I was required walk long distances to the garden and carried heavy bags of sago and taro up and down the mountains.

Look, think & act (strengths)

Mary's story 2

I knew it was important to have regular checks so I went to my antenatal clinics when I could.

One evening, in the eight month of my pregnancy, I was carrying heavy weights as I believe this strenuous activity brought on early labour. In my husband's village I was not allowed to stay in the house when I was in labour. I had to go to a sacred place to deliver and I could not wear clothes or take things that could later be returned to the house. **So being aware of those things,** I already packed the things that I needed in the bag to take with me to the hospital. And it was quite a long distance to walk to the main road in the hope that a vehicle would drive past so that you have a ride go to the hospital

Look, think & act (strengths)

Mary's story 3

It took three hours to walk to the nearest main village. Then I could not walk anymore. The pain was coming stronger. Because it was my first child I did not know what to do. This village was far from the road and it was a mountainous route. So I asked the local village women if they could help me so I could deliver in that village. But because I was not from that village they started preparing a birthing place away from the houses, somewhere in the bush where I could go to deliver.

Look, think & act (strengths)

Mary's story 4

Although women were around I felt I was there in isolation as no one was prepared to help me or come close to me that was the cultural norm. The village women told me I should push and if I did the pain would go away and the baby would come quickly. **And what I learned from high school about the reproductive system and I knew that you go through stages of delivery. I remember my mother said that when the water breaks and that is the time that the baby is ready to be born. And I was just thinking that they cannot tell me to push I wanted to wait until later.**

Look, think & act (strengths)

Mary's story 5

What made me strong at that time was I was praying all the time. I was crying through my pains. It took me the whole afternoon and all night to experience pain with no help or assistance from the local village women.

Look, think & act (strengths)

Look, Think and Act data generation and analysis framework

What has the participant chosen to talk about?' and 'what is important here?' This story is analysed concurrently using the traffic lights framework and provided to the participant as **feedback**. Rarely linear, the researcher invites the participant to **reflect** on the **feedback** and then 'we' continue talking and the story evolves.

Participant as co-researcher

This story is analysed concurrently and provided to the participant as feedback. Nina asks Mary to reflect on the feedback and then they continue talking as the story evolves.

And the story telling goes on and on 'in cycles' until both are satisfied with the 'end' product. What has Mary's learned from her experience? Based on her experience how does she believe maternal health can be improved in PNG?

Shaping the story with participants

Transcribed stories are treated analytically as units and so maintain their storyline rather than fragmented into thematic categories. The story is given structure by the **look, think** and **act** framework whilst extended storied accounts are preserved. The shaping of the story, the analysis of the narration and its editing is done in collaboration *with* participants.

Nina's progress

- In collaboration with PhD supervisors, four stories of birthing experienced in PNG were adequate for PAR learning, data generation, analysis, skill to write a 'common' story and facilitating PAR groups.
- This 'pilot study' ultimately deserved its own chapter in the writing of the thesis. Chapter 6 Phase 1 Apprenticeship in PAR Newcastle
- Nina's PAR apprenticeship was completed and she was an independent researcher /faciltator in the field for one year.
- Her PhD was awarded in 2013.

- One to one ongoing interviews with 4 Newcastle residing PNG women
- Tell me your story ...
- Recording & transcription
- **Look**, **Think** and **Act** **(and strengths)** data generation & analysis process
- Their words reworked into the story for individual feedback & validation
- Commonalities: many stories into one
- Participation in ongoing PAR cycles (4 sessions)

Preparation for PAR groups with Tina

- Start agenda, time & venue
- Introduction & notes
- Group norms, number of sessions & expectations clarified
- Facilitation / group dynamics
- Story telling (individual or common story)
- Digital recording & data management
- Transcription (what to transcribe)
- Analysis & **monitor actions**
- Researcher journal & **reflection**
- Timely feedback & invitation to respond
- Role of the literature review & sharing
- Evaluation of the PAR process

PAR group actions

- Four PNG women shared their stories and were surprised how little they had understood birthing
- The group suggested that an educative strategy might be the most useful in Nina's village but recognised that women would make these decisions themselves (they were mindful of literacy levels and male hierarchies in the village)
- The PAR group developed a Google Blog page: Promoting maternal health in PNG
- Four women offered to assist with wider networking
- Four women offered ongoing support to Nina for the duration of her PhD

PAR Apprenticeship Outcomes

- Nina Pangiau has earned her doctorate in 2013
- Jenny Day has her doctorate (2014): a PhD exploring family support in delirium care.
- Isabel Higgins position is now Professor of Nursing Older Person Care at the University of Newcastle, Australia 2008-
- Isabel Higgins and Tina Koch have supported five PhD candidates, all completed an apprenticeship in PAR processes.

Thank you

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