Why vulnerability matters more than risk

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Introduction

• Background
• The problematising (or not) of patient safety (post ISQua)
• Two promising methods
• Conclusion
Background

- Background and interests in:
  - Patient safety research and practice
  - Disaster theory and research
  - Population ageing research
  - Diversity work and research
  - Social sciences and humanities – sociology, demography, geography and philosophy
  - Spatial science – GIS, cartography etc
  - Health sciences – health management and leadership, health inequalities
Background: our project

Why is quality and safety in health care improving so slowly relative to the amount of money, strategies, programs, tools, technology, angst, effort, research and quality improvement projects, consultants, conferences and keynote speakers thrown at it?
Research base

• Study of 195 clinicians via 35 focus groups
• Focus on the understanding of patient safety
• Questions on risk but not specifically vulnerability
• Ongoing review of patient safety inquiries around the world
• A range of other patient safety related research projects, including on interprofessional teamwork
Example: vulnerability

- The question “who is most at risk in the health system?” received the resounding reply: “we are” from clinicians.
- Risk has been defined as a central cultural construct of recent times attracting significant attention in both the public and academic spheres: it is the possibility (or chance) of harm of loss to an individual or group, the magnitude of that loss or harm and the probability of its occurrence.
- Less is known about patients’ (either as individuals or in groups) vulnerability to harm. Vulnerability has been defined as susceptibility to any kind of harm (Little, 2000) whether physical, moral or spiritual, at the hands of an agent or agency, a factor which “… needs to be recognised and negotiated in health care transactions.” (Hurst, 2008)
What is vulnerability?

• Little et al (2000: 495) definition “…susceptibility to any kind of harm, whether physical, moral or spiritual, at the hands of an agent or agency” introduces both three important additional concepts:
  – the role of an external agent or agents
  – the notion of harm (either purposive or unintentional) and
  – the widening of the types of harm and safety beyond that of purely physical

• Vulnerability can be identified as occurring as a result of one or more social, structural, situational or other causes
Methodological challenges
(McCarthy et al, Caphaz, 2010)

- Variously defined and theorised
- No consistent set of metrics
- Are we analysing attributes or processes?
- Measurement at what scale? Time-space implications
- Who decides who is vulnerable?
- Are vulnerable groups visible?
- Are all members in a group (equally) vulnerable?
- Are the vulnerable included in the definition process?
- Who is responsible for addressing social vulnerabilities?
- Finite research and evidence base
Patient safety can be understood as a field

- Patient safety is a dynamic, contextual and contested construct
- This contestation can be seen as occurring within a field where various agents struggle over power, access to resources, and forms of capital, including symbolic capital
- The result is that some individuals, times, spaces, and places are "seen" as a risk or at risk, while others are not
The issue of vulnerability began to emerge early on ...
Who is at risk in the healthcare system?

1. Clinicians
2. Patients within specific contexts
3. Patients with specific characteristics
Clinician vulnerability

Vulnerability to external threats
• Political pressure
• Litigation
• The media

Professional vulnerability
• Competition between professions
• Junior and overseas trained staff
• Casual staff
• Competing priorities and demands
• Ability to have their opinions heard
• Ability to engage with the (public) health system

Vulnerabilities within the healthcare system
• Restructuring
• Competition within quality and safety agenda
• Management
• Service boundaries
• Service models
• Access to and discharge of, patients from services
What we know from our research

- Patient safety is a concern across all health professions and settings
- Clinicians experience a profound sense of vulnerability both for themselves and their families
- Medical errors are said to occur as a result of:
  - Poor communication
  - Ineffective teamwork
  - Cultural barriers
  - Inadequate or inappropriate resource management
  - Workforce and workload issues including lack of trained staff
  - But there is also something about the type of patient(s) …
The most clinically vulnerable patients are ...

- Those with liminal status;
- Rapidly deteriorating patients;
- Patients in transit;
- Patients discharged early;
- Patients in emergency departments and Intensive Care Units;
- Patients with co-morbidities and chronic illness
Who is at risk: social vulnerability and patient safety

- Older people
- People of Aboriginal and Torres Strait Islander background (members of Indigenous communities)
- Immigrants
- People with disabilities, especially cognitive impairments
- Children and youth
- Patients with literacy and communication problems
- People from lower SES

- Geographically isolated individuals
- Socially isolated individuals
- The homeless
- The frail and malnourished
- People with disabilities, especially people with mental illness, cognitive impairment, drug and alcohol problems
- The socially ‘undesirable’ (eg prisoners)
- ‘Difficult patients’
- Patients without an advocate in the system

Travaglia (2009)
Patient vulnerability: population groups

One that really stands out in my mind here was a mental health patient presenting to the ED. Just the way the system works, he was basically discharged from the ED but came back to the car park of the hospital in the evening and set himself alight in the car. You wonder what’s going on in the system if that’s the sort of event that occurs.
Patient vulnerability: population groups

In terms of malnutrition they say that up to 40 percent of adults and 60 percent of the elderly admitted to hospital are malnourished and they lose weight in hospital and then go home malnourished.

Data in Australia and around the world has shown that, and basically those patients are at an increased risk of infection, mortality in general, they’re weaker, not able to do their physio, so there are all those other issues as well. And up until recently there has been no community [nutritionist] positions, so basically they go home and they’ve got nothing and some of the oldies get even more malnourished at home.
Patient vulnerability: population groups

The situation that we’re in, in my job, we have that vulnerability forced upon our adult population and it’s doubled by the fact they’re inside a maximum security gaol as well. So their decision making and liberty is completely taken out of their hands.

The one thing that we do identify sort of from the door is issues around intellectual disability. That may be unique to this environment and not that they’re a more vulnerable group of people generally but certainly in this environment they are preyed upon. That makes a very big difference to how we manage them and how much attention or resource we can give to them.
A patient without an advocate, whether that be a nurse or relative as an advocate, I think that patient is at risk. My dad was in hospital last year and I wouldn’t leave his bed, I wanted to double-check everything that went through, everything he received. Anyone without an advocate I think is at risk.

Senior Nurse Manager
And every other one of the 30 focus groups conducted
### Taxonomy of patient vulnerability

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<th>Types</th>
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<td>Bio-genetic vulnerability</td>
<td>Demographic profiles and factors including age, individual health status, genetic predisposition</td>
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<td>Psycho-social vulnerability</td>
<td>Location, social and psychological factors, including presence of carers and/or family and friends, sexuality, disability, symbolic capital</td>
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<td>Epidemiological vulnerability</td>
<td>Groups and populations, both genetic and environmental illnesses and conditions</td>
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<td>Socio-economic vulnerability</td>
<td>Social, economic, cultural/religious, social and economic capital</td>
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<td>Spatio-temporal vulnerability</td>
<td>Time, space, physical transitions, environmental</td>
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<td>Inter-personal vulnerability</td>
<td>Relationship between patient and practitioner, &quot;difficult/problem clients&quot;, &quot;non-compliant&quot; clients</td>
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<td>Cultural vulnerability</td>
<td>Language, literacy, cultural and linguistic capital</td>
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<td>Practice vulnerability</td>
<td>Knowledge, skills, attitudes, stance of clinicians</td>
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<td>Team vulnerability</td>
<td>Communication, collaboration, peer relationships and pressures</td>
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<td>Structural vulnerability</td>
<td>Systemic, organisational, resources, media and public opinion</td>
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<td>Organisational vulnerability</td>
<td>Organisational, team, professional and local culture and relationships</td>
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<td>Environmental vulnerability</td>
<td>‘Natural’ disasters coupled with locational disadvantage, availability and timeliness of rescue and clean up services</td>
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The vulnerability of patients

I think all patients are at risk. I think we take them away from all their environment and put them into hospital and take away so much of their independence, their familiarity that they become very vulnerable.

While I agree it is about the elderly and it is about children, I think it’s all patients. I think mental health patients I would put into that mix. For a whole range of reasons because of what we do to people when they come into hospitals, we create that level of risk.
At the same time we started analysing patient inquiries and found similar patterns
What we know most about from inquiries

- Quality healthcare is not evenly distributed
- Health care can continue to operate far below standard for years, and sometimes decades
- Quality improvement processes are often deficient
- Poor communication (of all types) and poor teamwork will almost invariably be a contributing factor to any given error
- It is still not the norm for patients and families to be informed members of the healthcare team
- There is no clear pattern as to how, or whether, clinicians, patients or families concerns will be heard either in the healthcare system
- There is no clear pattern as to how, or whether the media, politicians or healthcare services will turn an individual case into an exemplar, although there are patterns
- Critics and whistleblowers are still generally ignored and abused, even after they leave the system

Hindle, Braithwaite, Travaglia (2006)
Mid Staffordshire is not atypical …

- The Ely Hospital, Wales (1967) - long stay patients, elderly
- Banstead Hospital, Cowley Road Hospital, Friern Hospital, St. James's Hospital, Storthes Hall Hospital, St. Lawrence's Hospital, Springfield Hospital, UK (1968) – elderly
- Normansfield Hospital, Middlesex, UK (1978) people with learning disabilities
- Inquiries into the circumstances of the death of various children and others and the first Ashworth Inquiry Ashworth, UK (1985-96) – children
- Stanley Road Hospital, Wakefield, UK (1986) – elderly patients
- Chelmsford Royal Commission, NSW (1990) – psychiatric patients
- Ashworth Special Hospital Inquiry, UK (1999) - criminal psychiatric patients
- Rodney Ledward, UK (1999) – women
- Cervical screening services at Kent and Canterbury Hospitals Trust - Wells Report, UK (1997) – women
- King Edward Memorial Hospital, WA (2000 – 2001) – women
- The Victoria Climbié Inquiry, UK (2001) – child
- RMH, Victoria (2002) - the elderly
- Southland DHB, NZ (2001-2002)- psychiatric patient
- Camden and Campbelltown Hospitals, NSW (2002-2003) – locational disadvantage, lower SES, people from NESB
- Shipman, UK (2005) - elderly women, isolated individuals
- Healthcare Commission, Clostridium difficile (Stoke Mandeville, Maidstone and Tumbridge Wells), UK (2006)
- Bundaberg, Patel Inquiries, Queensland (2006) – locational disadvantage, lower SES, Aboriginal and Torres Strait Islander patients
- E.coli Inquiry, South Wales (2006) – child
- Garling Inquiry Reeves, NSW (2008) – women;
- Garling Inquiry (acute healthcare), NSW (2008)
- Mid-Staffordshire General Hospital, UK (2010,2013) – ED, elderly, confused, dying patients
Why history is important…

• Medical experimentation on virtually all vulnerable groups
• The involvement of health practitioners in state sanctioned experimentation and torture
• Sterilization of Indigenous peoples, people with disabilities without their consent (continues)
• ‘Acquisition’ of bodies and body parts for study/display
The complex and relational nature of vulnerability
Vulnerability medicate care at all levels

World context (macro)
   Environment, economy, politics
   Differential burden of disease types and rates
   Human rights

Country and states (meso)
   Population(s) (demography, illness profiles, social determinants of health)
   Education, registration and monitoring of health workforce(s)
   Industrial relations, professional bodies
   Politics (internal and external), economic, culture and history of health systems
Vulnerability mediate care at all levels

Health services, teams and clinicians (micro)
  Organisation(s)’ history, location, capabilities and structure(s)
  Inter and intra professional relationships (clinician-clinician, clinician-manager, clinician patient)
  Workloads affected by amount of time required to care for people with comorbidities
  Use of agency and locum staff
  Competency

Patients, families and carers (micro)
  Involvement, control
  Accessibility of information
  Shared decision making
  Types and levels of risk, resilience, resources
What are the (social) connections between errors and safety and vulnerability?

- Context
- Sense-making of safety and errors
- Working assumptions of safety and errors
- Current strategies to improve safety and reduce errors
- Positive and negative consequences of attempts to improve safety and reduce errors
- Current limits of error reduction and safety improvement
- Future strategies
- Dilemmas
- Spatio-temporal dimensions
Vulnerability is cumulative and complex

- Know factors increasing risk
- Vulnerable individuals may be more open to cascades of errors (shown in the elderly)
  - more chronic and complex diseases, more medications, longer periods in hospital, higher risk of infection due to malnutrition etc – but little understanding of combination of factors – due to silo approach to care
- Unknown factors increasing risk (social attitudes eg obesity, racism or other forms of discrimination)
Factors contributing to cumulative vulnerability for PWDs

Each of these has a potential to **contribute** both to **errors of commission** and potentially more significantly, to **errors of omission** and to **cascade** errors

- **Poorer access** to all types and levels of health care;
- **Inappropriate environmental and design of equipment** (such as the height of examination beds);
- **Limited clinician inexperience** and **lack of training** in diagnosing and working with PWDs,
- ‘**Hyper-focus**’ on the disability rather than the individual and their other conditions or concerns;
- ‘**Diagnostic overshadowing**’ where symptoms are thought to be due to the person’s disability rather than an new or unrelated condition;
- **Increased probability** overall that health conditions to be **misdiagnosed or untreated**;
- **Patient difficulties** in expressing pain;
- **Lower levels of participation** in health care screening and preventative programs;
- **Lower levels of general or health literacy** on the part of patients;
- **Poor or inadequate communication** on the part of health care providers;
- **Lack of recognition of the concerns** of patients and family members.
Cumulative vulnerability to cascade errors for PWDs

Higher need for continuous, co-ordinated care
- Higher rates of preventable mortality, co-morbidity, and chronic conditions
- Mobility and transport problems, social and environmental barriers, and community and clinician misconceptions and assumptions
- Financial barriers, affect access to appropriate medical services and prescriptions

Lower levels of access to appropriate care
- Inaccessible services, including preventative, screening, primary, secondary and tertiary care
- Inappropriate or inaccessible equipment
- Lower levels of health literacy and difficulties in recognising and communicating health problems
- Inappropriate or inaccessible service information
- Lack of interpreters, advocates or support staff

Inexperienced services and clinicians
- Lack of appropriate undergraduate or postgraduate training
- Difficulties in communication between clinicians and clients
- Difficulties in diagnosis
- Problems in negotiating and undertaking procedures
- Issues with informed consent
- Require additional time during visits to address communication, cultural and language issues and review complex medical concerns

Lack of data collection and research
- Incident reporting systems do not include information on patient demographics contributing to errors
- Limited awareness of potential harm outside of specialist services
- Lack of research on the impact of disability on the risk of errors
- Limited uptake by the quality and safety movement of the specific needs and concerns of PWDs
Some additional perspectives
Practice/al implications

People’s practices, argued Bourdieu, are shaped by the field(s) within which they operate, which each field comprising a combination of:

… discourses, institutions, values, rules and regulations – which produce and transform attitudes and practices [as well as] … rituals, conventions, categories, designations, appointments and titles which constitute an objective hierarchy and which produce and authorise certain discourses and activities. But it is also constituted by, or out of, the conflict which is involved when groups or individuals attempt to determine what constitutes capital within a field, and how that capital is to be distributed … fields … are made up not simply of institutions and rules, but of the interactions between institutions, rules and practices.

There are holes in my structure: why the cheese matters

- Patient safety is constructed around a discourse that privileges key phrases and concepts, often received, mostly uncritical

- Risk and vulnerability are not evenly distributed: the cheese matters (even without the ANT pun)
And walls around my water

- Culture is created, and speaks to individual, group and organisational habitus
There is an overwhelming focus on findings patterns in errors, rather than in people or populations

- AHQR patient safety website
  - Papers on commission (286) – omission (46)
  - Indigenous, native, etc (0)
- Few if any error reporting systems collect or analyse population level data about incidents (eg gender, age, ethnicity, disability etc)
- Little mention of the ‘type’ of patient exposed to error – including across large scale inquiries, and in the recommendations and responses to those inquiries
And we still only know

- (Most) technological, organisational or policy ‘fixes’ versus changes in culture, hearts and minds
- (Most) commission versus omission errors
- (Most) causes versus impact of errors
- (Most) medical and medication errors versus errors in allied health, health promotion or public health
- (Most) doctors, nurses and pharmacists versus allied health and other professionals
- Clinicians versus patients
- How the gender, ethnicity, sexuality, socio-economic status, age, or any other social characteristic of either the clinician or patient affects the probability or impact of errors
What we still don’t know

- How the roles, remuneration, position and power of nurses, allied health and doctors affect the probability of error
- How to bring about cultural change, and whether this will necessarily result in positive outcomes for patients
- Short versus medium or long term causes and effects: professional, personal and organisational history matters!
- If, how and when training and education actually improves safety and how much education is enough
- How much the education and socialisation of health professionals contributes to errors “down the line”
- Whether any specific guidelines, policies or directives actually contribute to errors
- How much of a universal-local balance is enough
Patient safety circulates as a form of capital

- There are forms of risk and vulnerability that currently operate as "currency" in the health system.
- Organisational and professional culture may shape these conceptualizations.
- Instrumentalist notions of risk allow for ‘heroic’ responses.
- Robert Brooks – quality to safety, but not for all …
- Vulnerability operates in the disjunctures between contextualized placed relationships where risk is experienced, and
- Objectified spatial relations, where attempts to manage, contain or constrain risks occur through structural and systemic responses (would we tolerate the same rate of falls and medication errors in children?)
Medical errors have largely been disembodied

• Stories reflect individual experiences, but not population level patterns
• Gender and age are two of the most significant predictive factors in large scale breaches of patient safety around the world ... and yet ...
We need to problematise ‘patient centred care’

- The notion of patient-centred care needs to be problematised:
  - The patient versus the person versus the clinician versus the relationship
  - The expert patient as para-professional, expert etc
  - The representativeness of representatives
  - Ethics and modes of engagement with existing structures
  - The patient as person
  - The burden of responsibility and involvement
  - Preferential vulnerability
  - Institutionalized, cultural and individual inequities
  - Toleration of systemic absence of knowledge
  - Need for a relational understanding of healthcare
The symbolic nature of vulnerability

- Fricker (1980) concept of epistemic injustice
  - Both patients (denial of knowledge) and
  - Staff, in particular (but not only) allied health, nursing, and ancillary staff
- Bourdieu’s description of symbolic violence
  - Terminology
- Monique Lanoix - the citizen in question, Hypatia and the agelessness of modern citizenship theory in an era of population ageing
They are still dealing with elderly people. So I think there is a need for education, refocusing, particularly, there are growing numbers of elderly people going into the public hospital system and they call them bed blockers which I think is a dreadful term. It’s no wonder people develop an attitude that we shouldn’t be looking after them, they shouldn’t be here.

When you hear the minister or an area CEO coming out with, we have too many nursing home type patients in our beds, it’s almost as though it’s their fault …
(Possibly the most contentious) the ministerium of medicine in patient safety

• “Patient safety” was claimed immediately and completely by medicine
• Common adage ‘you cannot solve a problem from the same place it originated ...’
• The focus, even at major events is skewed almost entirely towards medical practice, with a focus on surgery (and related errors)
• Agents ability to access capital is affected by their ability to know and manipulate the “rules of the game”, and to utilise or overcome their habitus (embodied history).
• The powerful maintain their control over the field, and its resources through the use of doxa (that which is taken for granted) and manipulating less powerful agents into believing that “that’s the way we do things around here” (symbolic violence).
(Possibly the most contentious) the ministerium of (largely male) medicine

- Theories, approaches and ideas for remediation are drawn (understandably) from male dominated industries: planes, trains and automobiles
- Discussion on ‘soft skills’ - communication, teamwork still draw on dominant models
- The nursing research while philosophically more sophisticated has less impact
- Work in areas such as feminist geography and disaster studies which have explored vulnerability and risk comprehensively may offer new insights
There is not a good system of communication. It is very much ad hoc sometimes. We have many patients. One person says one thing and another person says something else. Doctors will often walk in and suggest sending someone home. The patient is from the country somewhere, so there is a lack of planning and lack of forethought in the communication. In addition, how far do you push things?

You do get to the point after so many years, of being tired of it all – the ethical side of it and the legal side of things. You sometimes feel that you are not doing as much as you can, but you know that the doctor does not want to do that sort of thing, so you back off ....
The importance of the concept of care

While an ethic of justice proceeds from the premise of equality - that everyone should be treated the same - an ethic of care rests on the premise of nonviolence - that no one should be hurt.

Carol Gillian
... and from Heidderger – a hint of epistemic humility (bit not from the man himself)

A fundamental basis of our being-in-the-world is for Heidegger, not matter or spirit, but care: Being-in-the-world has always dispersed itself or even split itself up into definite ways of Being-in - having to do with something, producing something, attending to something and looking after it, making use of something, giving something up and letting it go, undertaking, accomplishing, evincing, interrogating, considering, discussing, determining. . .

That something is care ...

Two examples

1. The use of data mining to expose underlying concepts
2. The use of GIS to explore patterns of vulnerability
Administrative staff’s view on safety and quality
Nurses’ views on safety and quality
Doctors’ views on safety and quality
Allied Health’s views on safety and quality
Managers’ views on quality and safety
Spatial forms of vulnerability
Spatial vulnerability model
NSW Ambulance Service Locations
NSW Aged Care Assessment Teams (ACATS)
NSW Meals on Wheels Service providers
Hospital locations
Accessibility to services
## Developing a Spatial Vulnerability Index

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<thead>
<tr>
<th>SA2</th>
<th>Relative SE Advantage</th>
<th>Relative SE Disadvantage</th>
<th>Economic Resources</th>
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Conclusion
Conclusion: a relational model of vulnerability
A new metaphor?

- Lucian Leape sparked off the patient safety movement in the US, by compared the error rates to jumbo jets falling from the sky
- Can ignoring vulnerability at a population level to errors be compared to the response (or lack of) to Hurricane Katrina