Carers as safety contributors in hospitals: From the periphery to partnership

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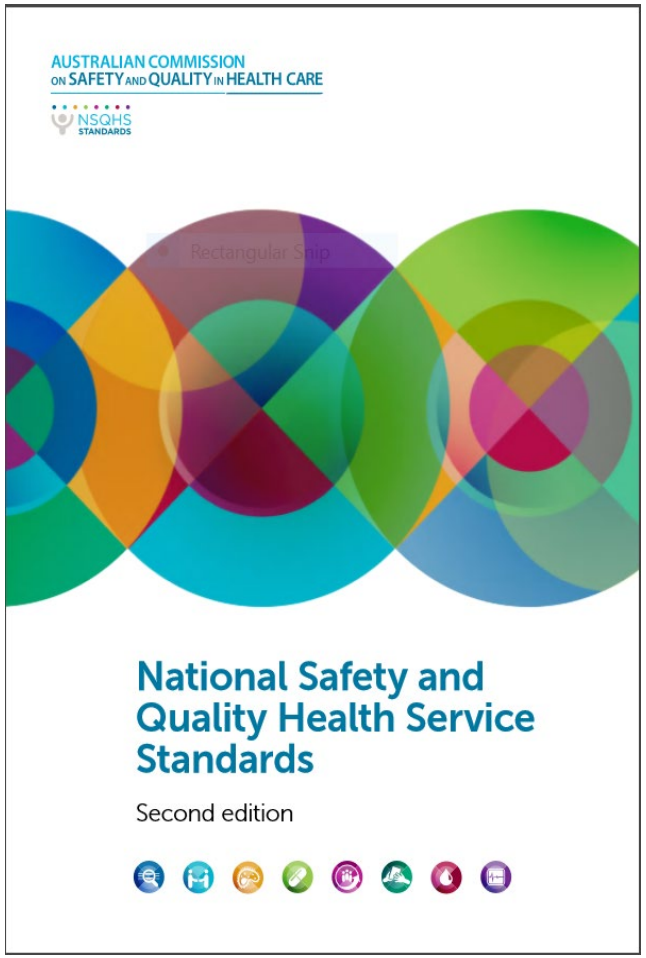
Session outline

- Why knowledge about carers' safety contributions is needed
- How carers contribute to safety and what could be improved
- Partnering in Healthcare framework
- SNEAK PREVIEW! New initiative in communicating about co-production (CoCoMaP)

People most vulnerable to harm in hospital

- Increased risk for people with:
  - communication disabilities (Bartlett et al 2008)
  - intellectual disabilities (Tuffrey-Wijne et al 2014)
  - dementia (Bail et al 2015)
  - frailty (Thornlow 2009)
- People in these groups often have a carer with them during at least some of their hospitalisation (Hemsley et al 2013; Iacono & Davis 2003; Webber et al 2010).

Carers as safety partners (National Standards)



Carers as safety partners (Vic. policy)

What does this mean for patients, families and carers?

Victorians deserve a system where patients have the information they need to know they are getting the best possible care. They need to be assured their voices are heard.

We will improve patient experiences by:

- listening to patient views and experiences of care at every point of the system and taking action to address their concerns
- ensuring all hospitals have an identified person responsible for addressing patient concerns, who is visible and accessible to patients, and able to meet a patient within a week of initial contact
- ensuring boards will be better connected to their communities to gain and maintain a broad perspective
- providing patient representatives with relevant personal experience to be part of clinical networks and the Victorian Clinical Council to help drive service improvement
- improving complaints management through better sharing of information between the Health Complaints Commission and Safer Care Victoria
- ensuring for the first time, mental health patients' experience of care across all levels of the mental health system will be measured to better understand what is working well and what areas need improvement
- using data provided in the first ever mental health services annual report to ensure we know where services are improving and expanding to meet growing demand and diversity, and where more needs to be done.

But…

What is happening *in practice*, from the *carers'* perspective?

Research aim

To understand how carers of adult patients perceived and experienced their contribution to medical error prevention in hospital

Methodology and methods

- Constructivist grounded theory (Charmaz 2014)
- Intensive individual interviews
- Carers recruited from health consumer organisations (Victoria, ACT and NSW)
- Carers…
  - of an adult patient admitted to hospital after 1 January 2013;
  - who visited the patient at least once during the hospitalisation; and
  - had concerns about the patient's care during the admission.

Participants

32 carers recruited and interviewed

- **Age range:** 24 to 74 years (mean=56 years).
- **Gender:** mostly female (n=29)
- **Education**: many were university educated (n=23)
- **Relationship to patient:** daughter/son (n=12), partner (n=10) or parent (n=7).
- **Diagnoses of patients:** wide range
- **Frequency of carer visits**: at least daily (n=23)

The process of 'patient-safety caring'

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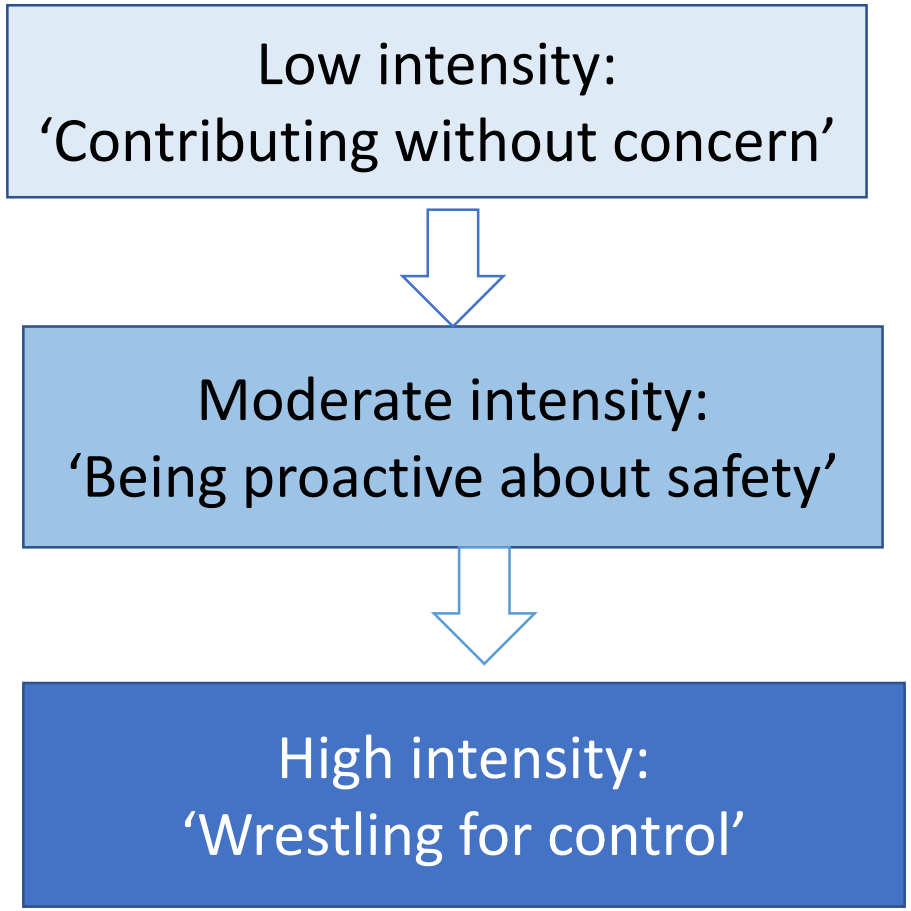
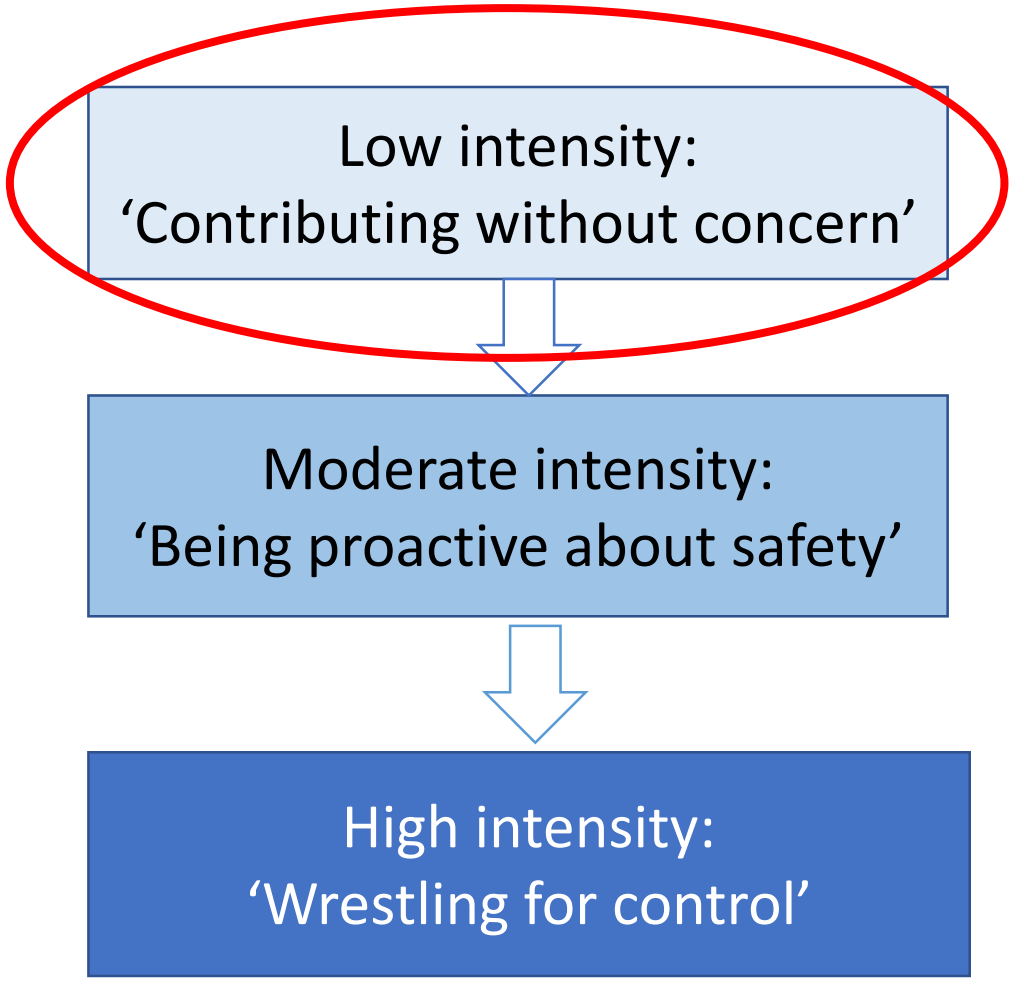


Low intensity: Contributing without concern



Low intensity: Contributing without concern (conditions)

- limited prior experiences of hospitals
- positive prior hospital experiences

Low intensity: Contributing without concern (actions)

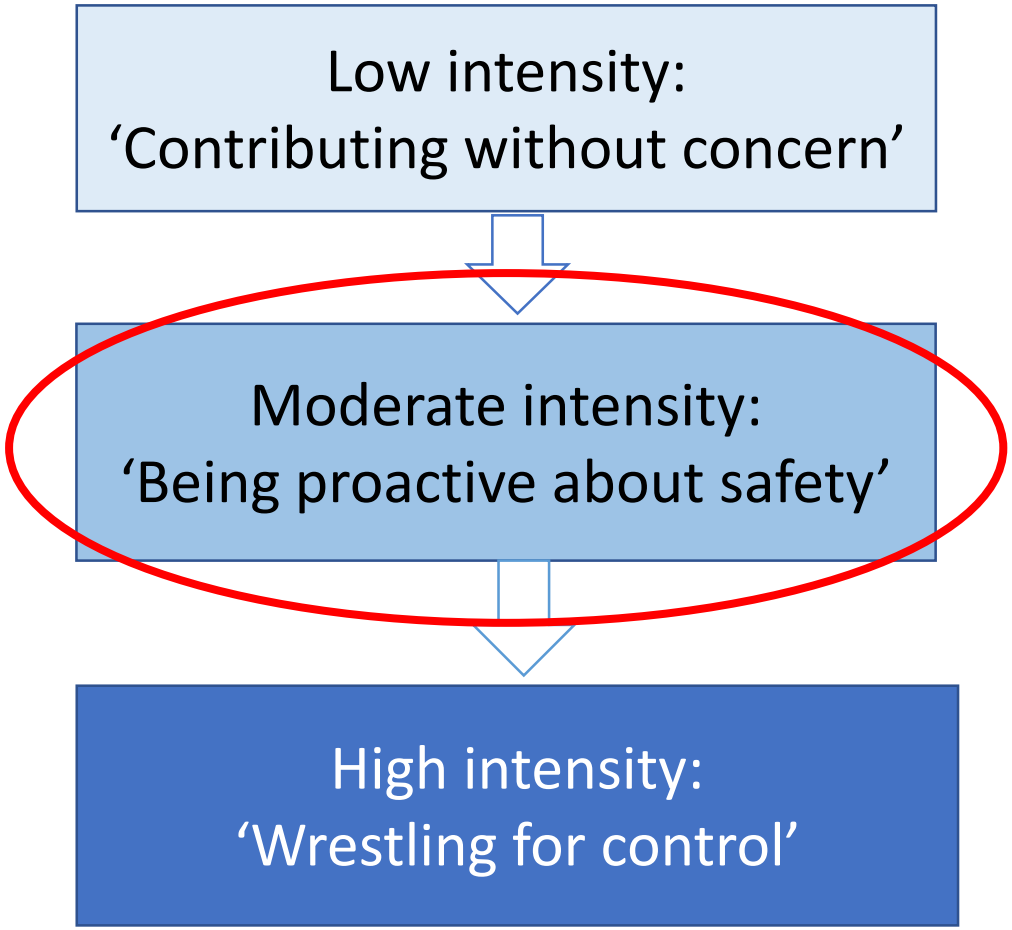
- Monitoring the patient
- Alerting the staff to safety hazards
- Awaiting treatment decisions

Low intensity: Contributing without concern (consequences)

- Feeling guilty after an adverse event:

"But after this doctor say "stop [the] medication", I didn't have [a] second thought. I just … forget about it. Just get on. But I just think, if I were more suspicious or ask[ed] [a] different doctor or find out more information about this medication … Is it really safe? … I can do better, you know. Yeah. I can do better."

Moderate intensity: Being proactive about safety



Moderate intensity: Being proactive about safety (conditions)

- Knowing the gaps in the system
- Encountering unresolved safety concerns
- Experiencing multiple safety concerns
- Perceiving the patient was at risk of serious harm

Moderate intensity: Being proactive about safety (conditions)

- Perceiving the patient was at risk of serious harm

"If Dad needed an extra blanket, big deal. But, if they're not getting medication they need and they can't walk or they're choking … you learn really quick when it's life-threatening and, you know, so serious. So you have to. You have to find a way."

Moderate intensity: Being proactive about safety (actions)

- Monitoring for safety hazards
- Participating in treatment decisions
- Facilitating the patient's involvement

Moderate intensity: Being proactive about safety (actions)

- Keeping the treatment trajectory on track

"And, yeah, there's also obviously not that follow-through because, every time you get handed from one person to another, you have to explain things all over again. You have to catch them up, you know."

Moderate intensity: Being proactive about safety (consequences)

- Feeling responsible

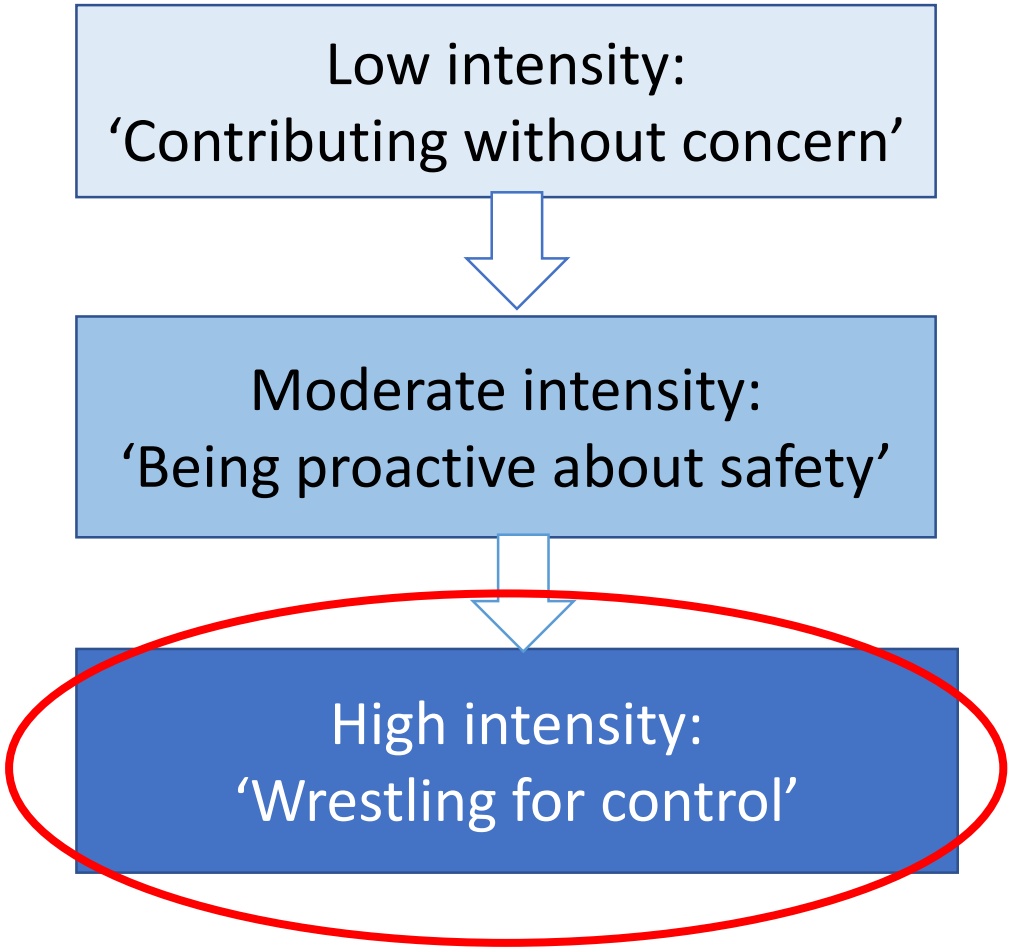
"So I try to sort of get there at the crack of dawn or whenever they allow you in, and then leave when, as late as they're ready to throw you out. I'm trying to stop situations before they happen because I'm scared."

Moderate intensity: Being proactive about safety (consequences)

- Feeling dismissed

"And all night this nurse kept coming in, shoving stuff into his drip, and we kept saying "What's that?" "Diazepam … diazepam … diazepam … just to stop the spasticity." And I said "But he doesn't *have* spasticity." "Yeah, look, we know what we're doing. We know what we're doing."

High intensity: Wrestling for control



High intensity: Wrestling for control (conditions)

- Experiencing harm
- Perceiving the staff were failing to resolve an imminent threat of harm

"When we go to hospital and she turns up with her adrenal crisis that needs urgent attention, with a protocol letter that says "Treat me urgently or I can die" three times out of the last four times we've gone to hospital we've had to fight with them about that, even though she has that letter. We've had to fight and fight and fight to get the help."

High intensity: Wrestling for control (actions)

- Monitoring for harm
- Taking control of treatment decisions
- Facilitating the patient's involvement

High intensity: Wrestling for control (actions)

- Fighting for action

"I raised merry hell about [mum's oxygen being disconnected] because I was really cross and the [nurse] said to me "Well we thought she was going to be moved really quickly." I said "I'm sorry, this is actually not okay" you know. Like "She's actually there. She's really, really vulnerable and she's got no oxygen, and you still can't tell me when she's going to move. Get the [expletive] oxygen!" I lost it completely."

High intensity: Wrestling for control (actions)

- Overseeing the treatment trajectory:

"You've got to do a checklist… You ring him up and say … "have they given you medication? … Has your dressing been changed?" … 'Cause, do you have to ring up the hospital and say "Ashley's supposed to have his x-ray today" or "Ashley's supposed to have his nephrology visit.""

High intensity: Wrestling for control (consequences)

- Preventing medical errors and harm
- Feeling responsible

High intensity: Wrestling for control (consequences)

- Experiencing hostility

"And I said "Look, she doesn't need a hot blanket. You know, she has heat reg(ulation problems)" and [the nurse] just turned around and snapped at me "Well she's got a *mouth! She* can tell me that!" And that's exactly how she said it. And I said "Well, actually, she can't. She has trouble communicating." And she got really, and she sort of huffed away and got really [expletive] with us."

Comparison of intensity levels

Low intensity: Contributing without concern	Moderate intensity: Being proactive about safety	High intensity: Wrestling for control
Monitoring the patient's condition	Monitoring for safety hazards	Monitoring for harm
Alerting the staff to safety hazards	Pursuing safety hazards	Fighting for action
Awaiting treatment decisions	Participating in treatment decisions	Taking control of treatment decisions
n/a	Keeping the patient's treatment on track	Overseeing the patient's treatment trajectory
n/a	Facilitating the patient's involvement in safety	Facilitating the patient's involvement in safety

Implications

- Carers have a lot to contribute to safety
- Carers often contribute in isolation rather than partnership → negative consequences for carers and staff
- Staff need to value carers, and carers need to feel valued
- Carers' impact on safety could be maximised with improved partnerships

Strengths and limitations of the research

Strengths:

- Recruiting from different states/territories potentially strengthened the applicability of the theory

Limitations:

- More diversity needed (e.g. men, CALD, non-tertiary educated)

Partnering in healthcare: Moving from the periphery to partnership

Source: Horvat (2019)

Domain 1: Personalised and holistic care

- Carers are often at the bedside for prolonged periods and observe issues others do not.
- During ward rounds or bedside rounding, invite (though do not require) carers to share observations of the patient's progress as well as their care.

Domain 2: Working together

- Demonstrate carers are valued team members by specifically inviting them to participate in care planning (e.g. through family meetings, or asking their opinion during treatment decision-making at the bedside)
- Delivering co-produced training to staff about safety issues involving carers' perspective

Domain 3: Shared decision-making

- Carers can provide valuable experiential knowledge about safety issues with particular treatments otherwise unknown to staff. Involve them in decision-making throughout admission via phone or in person
- Encourage carers to ask questions about particular treatments or medications.

Domain 4: Equity and inclusion

- Increase staff vigilance for safety issues for patients without carer or family support.

Domain 5: Effective communication

- Carers' experiences don't start afresh with each admission. The intensity level of their safety contribution may be reflective of prior experiences.
- Personally invite carers to provide regular feedback on safety issues as part of ward rounds or bedside rounding (don't rely on posters!).
- Real-time feedback mechanisms also useful

References

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New co-production resource

Do you want to learn more about how people are **co-producing care, health services and health research**?

Do you have **examples of co-production** you want to **share**?

Coming soon…

- Communicating Co-production in Health Research: Methods and Practice **(CoCoMaP)**
- An online platform for sharing examples of co-production in Victoria and beyond
- To be launched in 2020 by the Centre for Health Communication and Participation, La Trobe University

For updates about CoCoMaP:

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Thank you

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