
# Carers' contributions to preventing medical errors in hospital

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# Victorian Government vision

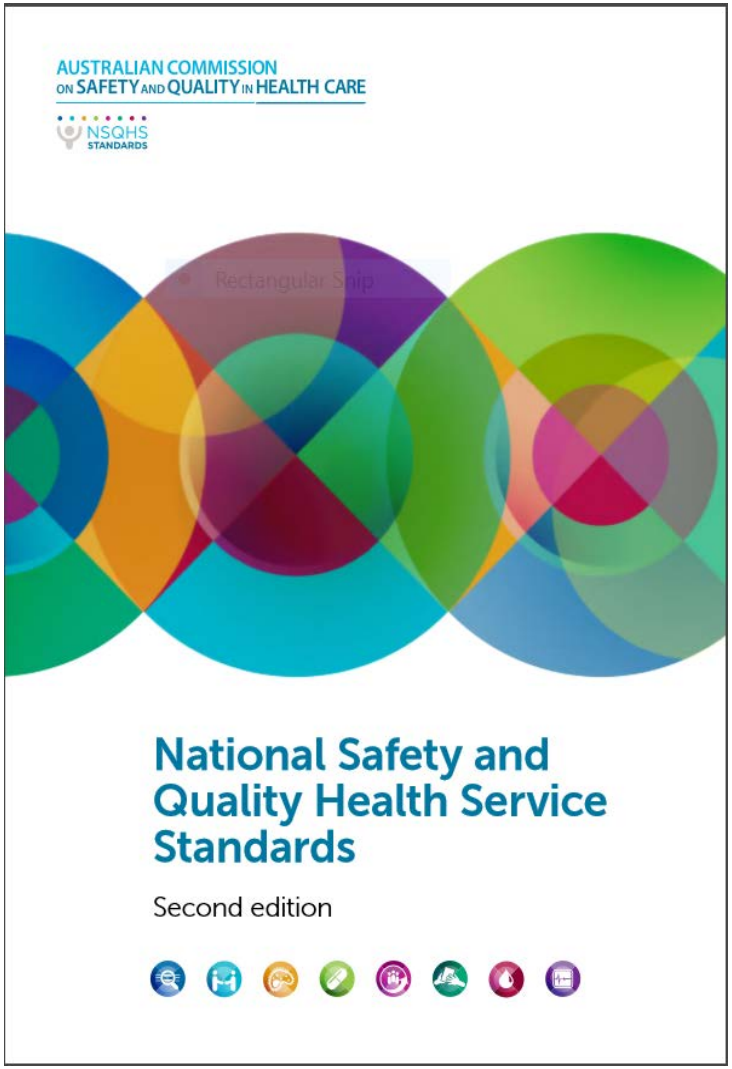
"…to achieve the best health, wellbeing and safety of all Victorians so that they can lead a life they value."

- 'Our strategy', Victorian Department of Health and Human Services website

# Reality (globally)

- Preventable healthcare-associated harm (particularly in hospitals) is a significant issue (Lamont & Waring 2015)
- 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 (Comm. policy)



# 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

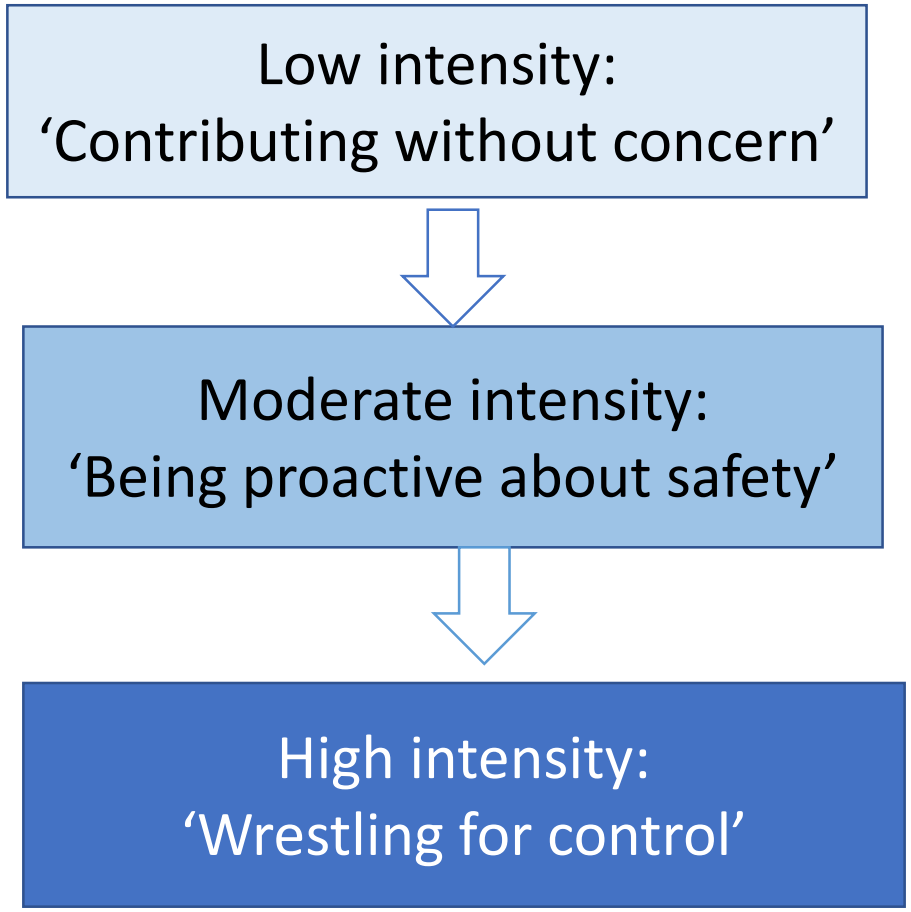
- **Methodology:** Constructivist grounded theory (Charmaz 2014)
- **Data collection:** Intensive individual interviews
- **Recruitment:** health consumer organisations in Victoria, ACT and NSW
- **Eligibility criteria:** Carers…
  - of an adult patient admitted to hospital after 1 January 2013;
  -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

# Participants

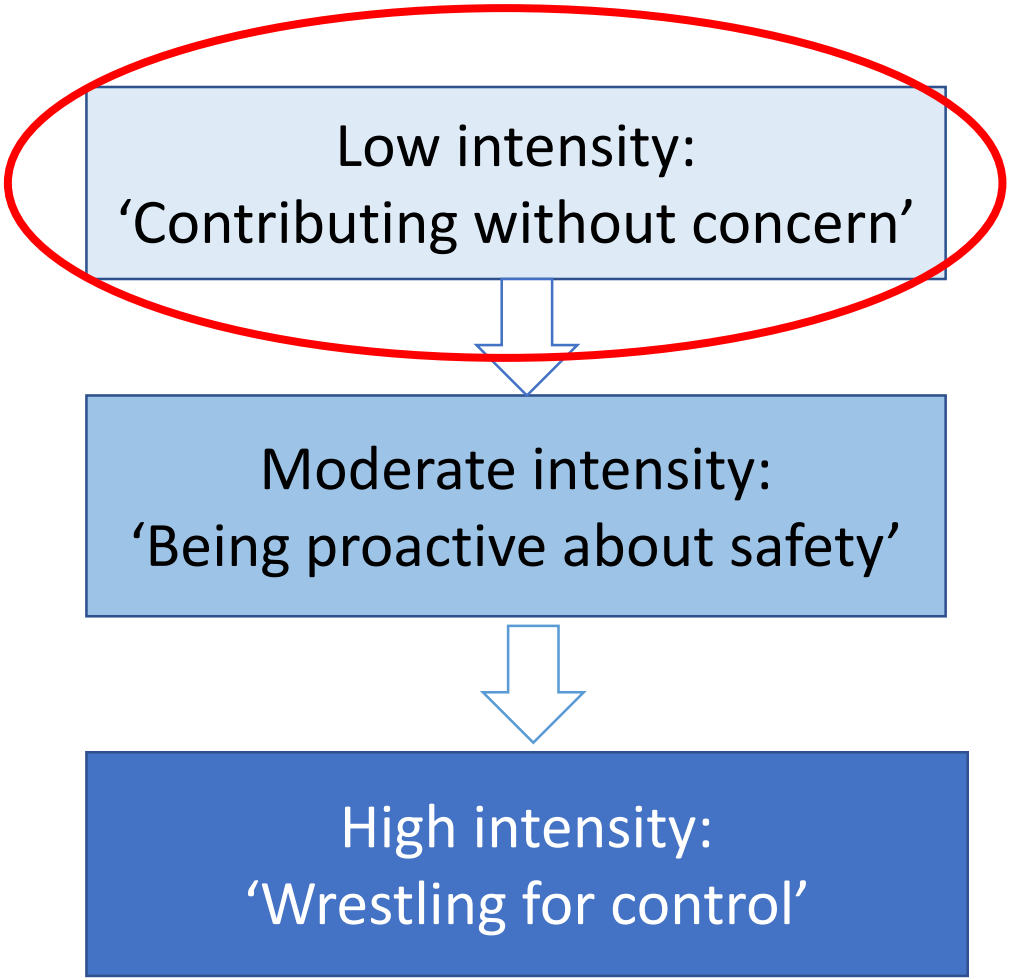
32 carers recruited and interviewed

- **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)

# Results: The process of 'patient-safety caring'



# Low intensity: Contributing without concern



# Low intensity: Contributing without concern

## Actions

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

# Low intensity: Contributing without concern

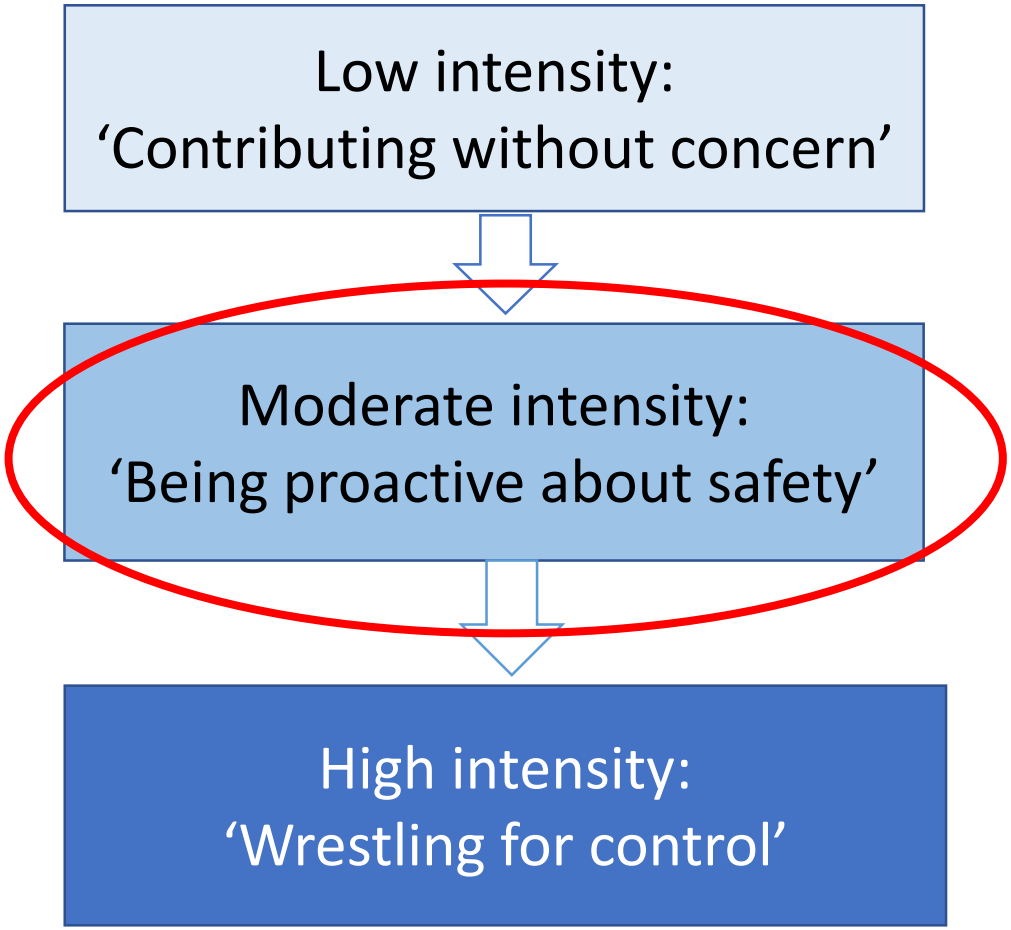
## Consequences

- 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."

*-Rita, 52 years, mother*

# 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

- 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."

*-Freya, 45 years, daughter*

# 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."

- *Felicity, 24 years, partner*

# 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."

*-Erin, 54 years, partner*

# Moderate intensity:

# Being proactive about safety

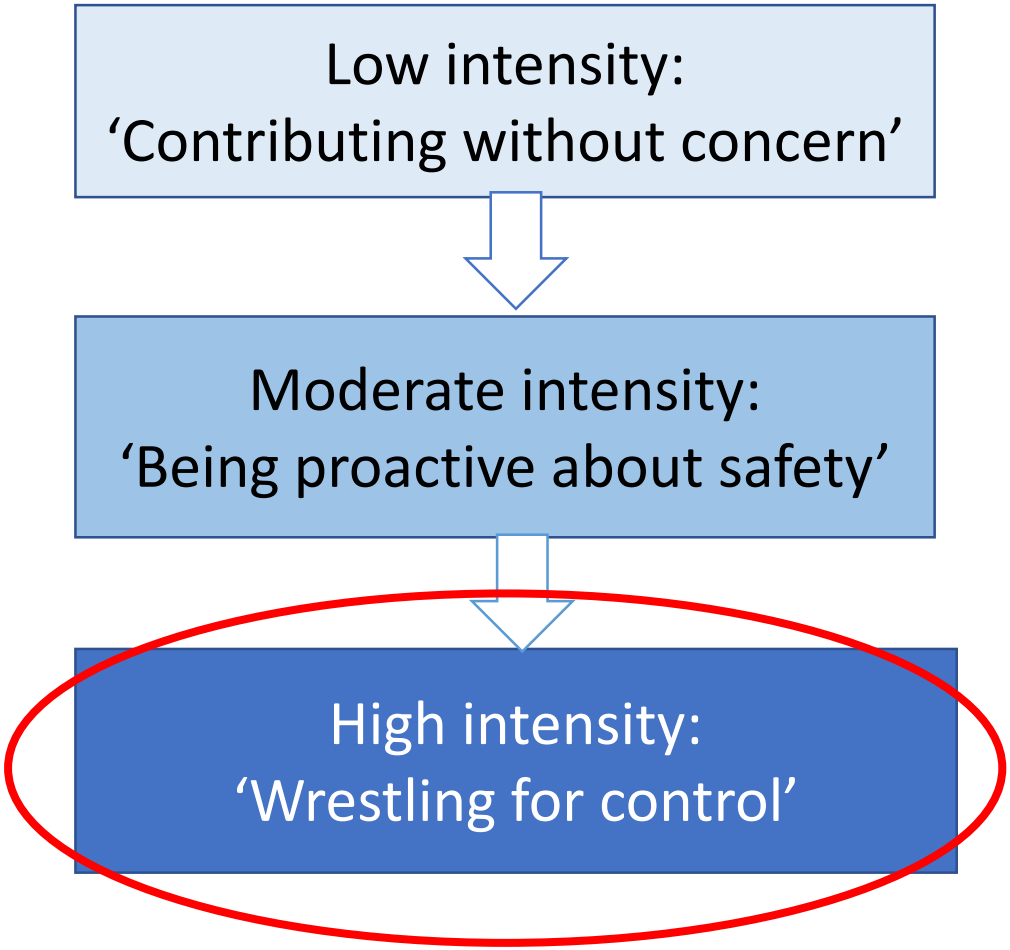
## Consequences

- 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."

*-Ingrid, 52 years, mother*

# 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."

*-Nina, 60 years, mother*

# 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."

*Georgia, 57 years, daughter*

# 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.""

*-Wendy, 48 years, mother*

# 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."

- *Nina, 60 years, mother*

# 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
- (What do patients without carers do?)

# Potential interventions to address policy/practice gap

- Targeting healthcare culture:
  - consumer involvement at all levels (already underway)
- Targeting training needs of the workforce:
  - (co-produced) training about the different ways carers can contribute to safety, and ways to facilitate their contributions

# Potential interventions to address policy/practice gap

- Shared decision-making:
  - Structure opportunities to help carers raise safety concerns (e.g. bedside ward rounds, family meetings)
  - Encourage (though not require) carers to share their observations of the patient's progress
  - Support carers to ask questions about particular treatments or medications
  - Open visitation and carer presence

# Patient and family-activated rapid escalation

- Carers can contribute to detecting rapid and subtle deterioration
- Carers may not feel confident to use a rapid escalation phone/button if other experiences contributing to safety have been negative
- Inviting carers to contribute to safety in other ways may help carers' confidence to use the button/make the call

# Carer feedback and complaints

- Carers can provide a good source of observations of safety that are not being captured
- Many reasons that carers do not complain
- Real-time carer survey systems (but will need encouragement to use them)
- Patient Opinion website

# Strategies for staff

- Healthcare professionals need resources to help them understand and support the different ways that carers can contribute to safety

# Strengths and limitations of the research

**Strengths:**

- Recruiting from different states/territories potentially strengthened the applicability of the theory
- Targeting carers who perceived there were safety problems, but had not necessarily experienced (or reported) an adverse event

**Limitations:**

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

# Ideas for future research

- Interviews with staff and patients on their perspectives on carers' contributions
- Studies using other research methods e.g. observation of carers in the inpatient setting
- Repeat current study using a different sample of participants

# Ideas for resource development


# Thank you

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