Patient Participation: A Practical Approach to Promote Patient Centred Care

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Outline

- Patient Centred Care and Patient Participation
- Patient Participation as a Patient Safety Strategy
- Research Program
  - Family Participation in Fundamental Care in ICU
  - Strategies to Promote Patient and Family Participation
  - Patient Participation in Bedside Handover
  - Patient Participation in Pressure Injury Prevention
Clarification of Terms

- **Patient-centred care:** The delivery of health care that is responsive to the needs and preferences of patients (ACSQHC 2011)
  - Requires power-sharing relationships that are collaborative and includes a ‘whole-person’ approach (Park 2018)
  - Core components: patient involvement in care, patient information, clinician-patient communication, patient empowerment (Park 2018)

- **Patient participation in care:** meaningful involvement of patients (and families) in decision about care, treatment and their well being - participation implies taking part or having a say in one’s care; also termed involvement or engagement; ‘the activated patient’

- **Patient involvement/participation/engagement a core aspect of PCC** (see for example Park et al, 2018 overview of 28 reviews)
Definitions of Patient Safety

- “Safety is the reduction of the risk of unnecessary harm to an acceptable minimum” (WHO 2009)

- “Safety is one dimension of quality” (IOM 2001); Quality care is:
  - Safe
  - Effective
  - Efficient
  - Timely
  - Equitable
  - Patient-centred
Patient and Family Participation as a Patient Safety Priority and Practical Approach to Patient Centred Care
Why Focus on Patient Participation or Engagement?

Positive outcomes associated with patient participation:

- **Chronic Conditions:**
  - Attainment of treatment goals (Arnetz et al., 2004; Rachmani et al., 2002)
  - Improved adherence (Wilson et al., 2009)
  - Reduced complications (Rachmani et al., 2002)
  - Improved health status – mostly chronic conditions (Dwamena et al., 2013; Cochrane review of 43 RCTs)

- **Acute Care:**
  - Half the rate of adverse events (OR 0.49, 95% CI 0.31 – 0.78) (Weingart et al., 2011)
  - Increased nurse and patient satisfaction (Weingart et al., 2011)
### Dimensions of Patient Participation in Care (PPC) (Sahlsten et al 2008)

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. An established relationship</td>
<td>Mutual, trusting, respectful, connected relationship.</td>
</tr>
<tr>
<td>2. Nurses’ surrender some power/control</td>
<td>Participation entails equality, negotiation, and responsibility.</td>
</tr>
<tr>
<td>3. Shared information and knowledge</td>
<td>Meaningful information exchanged between nurse and patient. Patient’s opinions, expectations, and experiences understood.</td>
</tr>
<tr>
<td>4. Active mutual agreement in intellectual and/or physical activities</td>
<td>Both nurses and patients engage in all aspects of care; Inviting, encouraging, and supporting are crucial.</td>
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</table>

Dimensions can be used by individual nurses to promote active patient and family engagement (micro level approach).
Patient Participation in Nursing Care

- Both patients and nurses say they want to promote patient participation but nurses’ behaviours are not always consistent with this.

- Patient condition and other individual factors influences their willingness and ability to participate.

- Nurses’ attitudes, their willingness to partner with patients and to share information and power influences patient participation.
Focus: Patient/family participation in nursing care (fundamental care, clinical handover and pressure injury/ulcer prevention)

• Family Participation in ICU ‘fundamental’ care: AUD $10,000 US$ 7,000 € 6,200

• Engaging Patients and Families in Clinical Communication: AUD $219,000 US$ 156,600 € 138,000

• Bedside Handover: AUD $266,000 US$ 193,400 € 169,000

• Patients’ and Nurses’ Preference for Participation in Patient Safety Activities: AUD $278,000 US$ 202,100 € 176,600

• Pressure Injury Prevention Care Bundle: AUD $1,071,000 US$ 778,700 € 680,200

• Quality nursing research is not cheap, but it represents value for money if you consider the savings from preventing adverse events/complications
Family Participation in Fundamental Care in ICU

- Focus groups with patients to identify what activities (intervention) they were interested in participating in
- Focus groups and surveys of nurses to identify what they thought about the proposed family interventions
  - Agreed an individualised approach, negotiating activities
- Trial: 2 similar adult ICUs; pre and post test in both the control and intervention sites
- Intervention: family and nurse negotiate what activities families wanted to participate in (tailored from a list)
- Outcome measure: Family Centred Care Survey (20 items)
  - 3 subscales: 1) respect; 2) collaboration; 3) support
## Results (Mitchell & Chaboyer 2009)

### Table: Characteristic Distribution

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Control (n = 75)</th>
<th>Intervention (n = 99)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient male</td>
<td>48 (65%)</td>
<td>65 (66.5%)</td>
</tr>
<tr>
<td>Family carer female</td>
<td>64 (85%)</td>
<td>74 (83%)</td>
</tr>
<tr>
<td>Carer was a partner</td>
<td>33 (44%)</td>
<td>48 (53%)</td>
</tr>
<tr>
<td>Carer was a child</td>
<td>23 (31%)</td>
<td>22 (23%)</td>
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</table>

Families participated in:

- Massage (29%), bath (23%), eye care (17%), other (mouth care, comb hair, antithrombolic stockings etc)

Family Centred Care Survey reliable (Cronbach's alpha pre: 0.84 post: 0.83)

Family participation in care was the strongest predictor of positive FCC survey results: intervention group 1.5 times as likely to report high FCC score

A ward level approach to active family participation (meso approach)
Case Study:

- **Aim:** identify exemplars in practice
- **5 Cases:** 7 hospitals in 4 states, identified with the funder’s assistance
- **Key stakeholders,** identified by site leaders
- **Individual or group audiotaped interviews**
- **N =** 62 participants (27 individual, 11 group)
- **Variety of participants including patients, carers, patient advocates**
### Strategies to Involve Patients/Families

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td><strong>Bedside handover</strong></td>
<td>Patient +/- family participate in nursing handover</td>
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<tr>
<td><strong>Multidisciplinary bedside rounds</strong></td>
<td>Include a formal process to invite pts/families and bedside nurse to contribute. Some called SIBR (Structured Interdisciplinary Bedside Rounds)</td>
</tr>
<tr>
<td><strong>Nursing hourly rounding</strong></td>
<td>Opportunity for both patients/families to share information and nurses to respond to patients in a timely manner</td>
</tr>
<tr>
<td><strong>Leader rounds</strong></td>
<td>Visit patients/families, asking them about their experiences, preferences and plans and any issues they have</td>
</tr>
<tr>
<td><strong>Case conferencing</strong></td>
<td>Multidisciplinary and includes patient/family to ensure all are included in the care planning</td>
</tr>
<tr>
<td><strong>Pt led discharge</strong></td>
<td>Patient/family negotiate discharge timing</td>
</tr>
<tr>
<td><strong>Team training</strong></td>
<td>Staff taught to ‘speak up’ about safety concerns and to facilitate patient/family engagement</td>
</tr>
</tbody>
</table>

Examples of meso and macro approaches to patient and family participation
Why Handover Research?

Substandard H/O may result in:

- Delay in treatment
- Inappropriate treatment
- Adverse events
- Omission of care
- Increased costs
- Inefficiency from rework

<table>
<thead>
<tr>
<th>Survey Respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The attending physician</td>
</tr>
<tr>
<td>Consulting physician</td>
</tr>
<tr>
<td>Another resident physician</td>
</tr>
<tr>
<td>Nurse or technician</td>
</tr>
<tr>
<td>Patient or patient's family</td>
</tr>
</tbody>
</table>

The Joint Commission Center for Transforming Healthcare.
Nursing Bedside Handover Research

- **Aim:** To describe the structures, processes and outcomes of nursing shift-to-shift bedside handover

- **Design:** Case study

- **Sample:** 6 wards in 2 Australian Hospitals (Queensland and Western Australia)

- **Data Collection:**
  - Observation of bedside handovers for 5 days in each ward
  - In-depth interviews with nurses, patients and their families
Bedside Handover Results

- 532 bedside handovers observed (6 wards, 2 hospitals, 2 states)
- Average length of handover 1 minute 16 seconds (±51 sec)
- Interviews: 34 with nurses, 10 with patients, 10 with families

**Structures**
1. Staff
2. Patients
3. Handover sheet
4. Bedside chart

**Processes**
1. Prior to handover
2. During handover
   - Content
   - Safety scan
   - Confidentiality
   - SBAR
3. After handover

**Outcomes**
1. Staff experience
2. Patient experience
3. Family experience

Emeritus Prof Anne McMurray
Prof Marianne Wallis
- Chaboyer et al 2010
- McMurray et al 2010, 2011
- Tobiano et al. 2013
Outcomes (Interviews)

- Patients feel part of the handover process and have input into their care
- More accurate information is communicated
- Better understanding of patients’ conditions is gained
- Patients are visually ‘seen’ sooner in the shift
- Continuity of care is improved
- Patient can prompt recall of important events and issues
- Improves communication among staff at change of shift
- More opportunities for teaching and modelling behaviours
- Can be less time-consuming
Medication Errors
(P-chart for proportion)

- P-Chart: Proportion of harm of medication errors (3 wards)
- Similar pattern for PI but not for falls with injury

8 successive points on the one side of the mean indicating process improvement
Bedside Handover
Implementation Issues

• Move to bedside handover must be driven by need to improve handover

• Buy-in from staff is required

• Change management process is crucial: ex. Lewin’s 3 Step Model – Unfreezing, Moving, Refreezing

• Avoid ‘talking over’ patients; limit the use of medical jargon

• Explicit encouragement of patient involvement is needed

• Strategy for non-patient related handover information is needed

• Series of publications: Chaboyer et al., McMurray et all. Tobiano et al.
Patients’ & Nurses’ Preference for Participation in Patient Safety Activities

- **Phase 1:** Interviews with 20 patients and 20 nurses and observations (PhD)
  - 4 wards in 2 hospitals (1 public, 1 private) in 2 states

- **Phase 2:** Survey of patients and nurses regarding bedside handover (DCE)
  - 400 pts, 200 nurses

- Wendy Chaboyer
- Prof Jenny Whitty
- Prof Tracey Bucknall
- Georgia Tobiano (PhD student)
Phase 1: Interview Findings
(Tobiano et al., 2015 a,b)

<table>
<thead>
<tr>
<th>Patient</th>
<th>Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>On the lookout</strong>: monitoring treatment, monitoring information, checking environmental safety</td>
<td><strong>Managing risk</strong>: regulating medications, controlling pressure area care, following rules, gauging patient capabilities, assessing the environment</td>
</tr>
<tr>
<td><strong>Exchanging intelligence</strong>: sharing knowledge, seeking understanding</td>
<td><strong>Acknowledging patients as participants</strong>: honouring patient choices, respecting patient’s knowledge</td>
</tr>
<tr>
<td><strong>Imbalances in power</strong>: complying with nurses, feeling helpless, relying on nurses for assistance, nurses’ manners</td>
<td><strong>Enabling participation</strong>: familiarity with the patient, individualised experiences, encouraging independence</td>
</tr>
<tr>
<td><strong>Valuing participation</strong>: beneficial to participate, personal disposition to participate</td>
<td><strong>Realising participation</strong>: contributing to clinical communication, participating in activities</td>
</tr>
</tbody>
</table>
Observational Findings

- A total of 58 hours of observation (½ day ½ evening shifts)
- 28 patient-nurse ‘dyads’
- 116 patient-nurse encounters
Discrete Choice Experiment
(Spinks et al, 2015)

- 400 patients and 200 nurses in two hospitals
- Survey on ipads

<table>
<thead>
<tr>
<th>I am invited to participate:</th>
<th>Handover A at your bedside</th>
<th>Handover B at your bedside</th>
<th>I would prefer handover to happen away from my bedside</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of nurses present at the handover:</th>
<th>Handover A at your bedside</th>
<th>Handover B at your bedside</th>
<th>I would prefer handover to happen away from my bedside</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only the nurse leaving and the nurse coming on</td>
<td></td>
<td>The nursing TEAM leaving and the TEAM coming on</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family member, carer, or trusted friend allowed to be present:</th>
<th>Handover A at your bedside</th>
<th>Handover B at your bedside</th>
<th>I would prefer handover to happen away from my bedside</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My level of involvement:</th>
<th>Handover A at your bedside</th>
<th>Handover B at your bedside</th>
<th>I would prefer handover to happen away from my bedside</th>
</tr>
</thead>
<tbody>
<tr>
<td>I hear what is said and I am asked questions</td>
<td>I hear what is said, I am asked questions and I can speak up at any time</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What information related to your care is discussed:</th>
<th>Handover A at your bedside</th>
<th>Handover B at your bedside</th>
<th>I would prefer handover to happen away from my bedside</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information about my medical condition and plan for care</td>
<td></td>
<td>Information about my medical condition only</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Confidentiality and privacy:</th>
<th>Handover A at your bedside</th>
<th>Handover B at your bedside</th>
<th>I would prefer handover to happen away from my bedside</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitive information is handed over verbally away from my bedside</td>
<td>Sensitive information is handed over in written form</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please choose:
• Both patient and nurses identified patients being invited to participate in the handover was the most important

• Both patient and nurses identified having patients actively participate was also important

• Nurses preferred sensitive information to be written on handover sheet only but patients preferred it to be stated quietly at the bedside

• An example of a ward level (meso) approach to patient participation
Summary and Implications

- Invite patients/families to actively participate in handover:
  - Most important part of handover
  - Can be viewed as disruptive (can be overcome)

- Confidentiality:
  - Greater concern for nurses than patients

- Patient factors:
  - No one-fit-all approach

- Family member/carer/friend presence:
  - Patients desire this more than nurses

- Number of nurses present:
  - Fewer nurses preferred
Patient Centred Pressure Injury Prevention Care Bundle (PIPCB)

- Pressure Injury Prevention is one concrete way patients may be able to participate in their care
- Developed and feasibility tested a patient centred PIPCB based on active patient participation
- Tested the PIPCB in a multi-site cluster RCT focusing on clinical effectiveness, cost effectiveness
- Process evaluation to better ‘understand’ how the PIPCB ‘worked’ or ‘did not work’
Background to Developing the PIP Care Bundle

- **Clinical Practice Guidelines for PIP** (AWMA 2012, EPUAP/NPUAP 2009, EPUAP/NPUAP 2014)

- **Adherence to PIP strategies is sub-optimal** (Vanderwee 2011, Gunningberg 2005, Latimer 2016)

- **Australian National Safety and Quality Health Service Standards** (2011)
  - Consumer Participation
  - Preventing Pressure Injuries

- **Care bundles are groups of interventions, that together improve patient care and outcomes** (IHI 2013)
Care bundle to prevent PI, incorporating:

- Patient participation in care
- Patient education on PIP
- Engaging nursing staff in patient participation

Three main messages:
1. Keep moving
2. Look after your skin
3. Eat a healthy diet

Resources:
1. 5-minute DVD
2. Poster
3. Brochure
Assessing the PIPCB’s Effectiveness (NHMRC)

Prof Tracey Bucknall

Prof Joan Webster

Prof Liz McInnes

Dr Merrilyn Banks

Prof Marianne Wallis

Prof Brigid Gillespie

Prof Jenny Whitty

Prof Lukman Thalib

Prof Nicky Cullum
Main Trial

- **Design**: Cluster Randomised Trial (c-RT)
- **Clusters**: 8 hospitals (public/private, 200+ beds), stratified by most recent PI rates and randomised 1:1 block allocation
- **Recruitment**: 1,600 patients (200/site)
- **Sample**: Patients at risk of PI as demonstrated by limited mobility (in hospital < 36 hours prior to recruitment)
- **Primary outcome**: incidence of hospital acquired PI (HAPI) – daily skin inspection (blinded outcome assessors; daily skin assessment)
- **Process evaluation and cost-effectiveness analysis**
- Australian New Zealand Clinical Trials Registry (registration number ACTRN12613001343796)
- Protocol published: International Journal of Nursing Studies
Assessed for eligibility n = 8 sites (clusters)

Randomised n = 8 clusters

Excluded n = 0

Allocated to PIPCB n = 4 clusters

Consented n = 800
1 patient excluded after consent (confused)

0 clusters LTFU
22 patients LTFU (2.8%)
20 patients withdrew consent (2.5%)

4 clusters analysed
Average cluster size (SD) n = 189.3 (5.7)
799 patients analysed of which 6 died

Allocated to standard care n = 4 clusters

Consented n = 800
1 patient excluded after consent (confused)

0 clusters LTFU
9 patients LTFU (1.9%)
12 patients withdrew consent (1.5%)

4 clusters analysed
Average cluster size (SD) n = 194.5 (1.3)
799 patients analysed of which 3 died
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>PIPCB n = 799</th>
<th>Control n = 799</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>393 (49.2%)</td>
<td>434 (54.3%)</td>
</tr>
<tr>
<td>Medical</td>
<td>558 (69.8%)</td>
<td>463 (57.9%)</td>
</tr>
<tr>
<td>Surgical</td>
<td>232 (29.0%)</td>
<td>316 (39.5%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>9 (1.1%)</td>
<td>20 (2.5%)</td>
</tr>
<tr>
<td>Number of co-morbidities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N % of patients with 1</td>
<td>207 (25.9%)</td>
<td>232 (29.0%)</td>
</tr>
<tr>
<td>N % of patients with 2</td>
<td>197 (24.7%)</td>
<td>193 (24.2%)</td>
</tr>
<tr>
<td>N % of patients 3 or more</td>
<td>207 (25.9%)</td>
<td>181 (22.6%)</td>
</tr>
<tr>
<td>Current Smoker</td>
<td>50 (6.3%)</td>
<td>49 (6.1%)</td>
</tr>
<tr>
<td>Number of PU present on baseline</td>
<td>60 (7.7%)</td>
<td>95 (12.0%)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>70.0 (20.0)</td>
<td>74.0 (22.0)</td>
</tr>
<tr>
<td>Median (IQR) range</td>
<td>18.0-100.0</td>
<td>19.0-104.0</td>
</tr>
<tr>
<td>BMI</td>
<td>27.4 (7.4)</td>
<td>27.0 (7.6)</td>
</tr>
<tr>
<td>Median (IQR) range</td>
<td>13.1-65.7</td>
<td>14.5-69.4</td>
</tr>
<tr>
<td>Hospital length of stay (days)</td>
<td>6.0 (5.0)</td>
<td>5.0 (5.0)</td>
</tr>
<tr>
<td>Median (IQR) range</td>
<td>1-77</td>
<td>1-97</td>
</tr>
</tbody>
</table>
Results

- Mean time spent delivering the PIPCB $9.6 \pm 5.4$ minutes
- HAPI: PIPCB $n = 49$ (6.1%); Control $n = 84$ (10.5%)
- Taking into consideration the follow up days in the study, the incidence rate:
  - PIPCB group 11.1/1000 days
  - Control group 23.5/1000 days
- Incidence rate ratio of 2.1 (95% CI: 1.5 to 3.0; p value <0.001)
Process evaluations seek to understand what parts of the intervention worked and did not work and in which contexts.

- The PIPCB was thought to be easy to incorporate into routine practice.
- Nurses thought it supported their current practices.
- Patients liked the DVD, poster and brochure.
- Overall, the process evaluation was positive.
Translating CPG to Practice: patient education brochure
(Arabic, Chinese, Spanish, Vietnamese, Italian, Greek, Croatian, Somali)
Patient education poster

Implementation Toolkit

- Describes the resources
- Identifies the requisites for patient participation in nursing care
- Suggests a 4-step process to implement the resources
- Provides an example of an implementation plan
- Includes a short (6-slide) powerpoint
- Explains options for evaluating the use of the resources
- Includes a valid and reliable measure of patient participation in PIP
- Lists the publication (evidence) for the resources
Conclusion

- Patient and family participation is a practical way to enact patient centred care
- Nurses have been viewed as a ‘safety mechanism’ with the ability to prevent some errors from harming the patient
- Active patient/family participation is another strategy recommended to promote patient safety (partnering with nurses)
- Patient/family participation can occur at the micro (individual nurse) meso (ward) or macro (hospital or system) level
- While one size does not fit all, many patients/families are willing and able to participate in some way
- Active management of the implementation process is needed to capitalise on patients’ participation (change management)
Thank you for listening