What A Family Perspective Teaches About Adverse Events In The Pediatric Setting

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Disclosures and Conflicts

I have no actual or potential conflict of interest in relation to this program.

I and my co-authors assume responsibility for ensuring the scientific validity, objectivity, and completeness of the content of my presentation.

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Learning Objectives

• Recognize the differences in how families and health care providers:
  – understand adverse events
  – how they report such events

• Appreciate the value of patient and family input arising from adverse events in a pediatric setting
How can we be safer?

The 1 source of experience and expertise that remains largely ignored is that of the patient!!!
Patients for Patient Safety is an international network of patients and family members who have experienced preventable harm in the health-care system, as well as patient advocates, policy-makers, health-care workers and others, from the developed and the developing world, dedicated to improving patient safety through partnership.

Patients for Patient Safety:

- believes that safety will be improved if patients are included as full partners in reform initiatives
- promotes patient engagement, patient empowerment, patient leadership and involvement in the creation and dissemination of patient safety initiatives
- is led by patients and guided by the values expressed in the London Declaration

The collective wisdom, determination and passion of the global patient population is a rich resource in the global endeavour to improve the safety of health-care practices.
Long after we remember the words you used, we will remember how you made us feel - Deb Prowse
Adverse events among children in Canadian hospitals: the Canadian Paediatric Adverse Events Study

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Family Perspective

• Families and patients keen observers
• They interpret a safety related event in their own context
• They can provide vivid and articulate accounts of experiences
• Illustrate the impacts of harm in many ways and to many degrees
• The how is (perhaps) more important than that what
Harmful Events: The Patient & Family Perspective

A Systematic Review

Janice McVeety RN. MHA.
Lisa Keeping-Burke RN. PhD.
Christina Godfrey RN. PhD.
Amanda Ross-White BA. MLS.

Queen's University

QJBC
Queen's Joint Health Care Coordination: A pan-Canadian collaboration for synthesis of evidence in Patient Safety

Practice and Research in Nursing (PRN)
Patient / Family Perspective

- Violations of trust
- Communication
  - Patient and family member not listened to
  - Effective
- Disclosure process
- Apology
  - Actions to be congruent with apology
Patient / Family Perspective

- Consequences and impact of the harm event
  - Physical and financial as well as emotional
- Fears of reprisal/interference with care
- Learned helplessness
  - Tired to report and it would not make any difference
- Measure of safeguarding
  - Having to act as their child’s protector
- Self-discovery and awareness of errors
  - Knowing but having to prove
Time to listen: a review of methods to solicit patient reports of adverse events

A King,¹ J Daniels,¹ J Lim,¹ D D Cochrane,² A Taylor,³ J M Ansermino¹
Optimal Methodologies

• Question Structure
  – Open ended
  – Asked about personal experiences

• Recall bias

• Recruiting and interview in person by a neutral individual
A human factors and survey methodology-based design of a web-based adverse event reporting system for families

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Family Reporting System (FRS)

- Relevance
- Face Validity
- Usability
- Repeatability
- Utility
Bedside Observer Reporting Survey

At any time during the study, you are welcome to select:

- **FAQ** for additional information and frequently asked questions
- **Consent Form** to access a copy of the complete study consent form

Please complete this survey with information concerning your child's most recent hospital stay.

Directions:

Click ✚ to add a problem or concern to your report. You may add multiple problems or concerns if necessary (Note: 'Ctrl' / select allows for easy multiple additions)

Click ✗ to remove problem or concern from your report

You must complete sections marked with a ✦

You can click ❓ for more examples of types of problems/concerns
# Bedside Observer Report

## Section 1: Medication Problems
When a medication is not given exactly as it was meant to be.

* Do you think a medication problem occurred or was stopped before occurring?  

Examples:
- Medicine given in the incorrect amount  
- Incorrect medicine given

## Section 2: Complications of Care
When there is an unwanted result of a treatment.

* Do you think a complication of care occurred or was stopped before occurring?  

Examples:
- Unexpected bleeding occurred  
- Unexpected transfer to intensive care unit

## Section 3: Equipment Problems
When equipment fails or is not used correctly.

* Do you think an equipment problem occurred or was stopped before occurring?  

Examples:
- Equipment was not available when needed  
- An intravenous line leaked or became blocked

## Section 4: Miscommunications between Staff
When members of the staff give information to or receive information from other staff about diagnosis, treatment or care that is inadequate (not enough information they gave) or incorrect.

* Do you think a miscommunication between staff occurred or was stopped before occurring?  

Examples:
- A test was repeated because the sample was lost  
- A test was cancelled by mistake

## Section 5: Miscommunications between You or Your Family and Staff
When you, your family, or staff give or receive information about diagnosis, treatment or care that is inadequate (not enough information), conflicting (information they gave) or incorrect.

* Do you think a miscommunication between your or your family and staff occurred or was stopped before occurring?  

Examples:
- Medication instructions were not explained to you  
- Test results were not provided to you

## Section 6: Other Problems
When any action not previously described fails or is the incorrect action.

* Do you think any other problems occurred or were stopped before occurring?  

Examples:
- A burn occurred during surgery  
- A bruise occurred after bloodwork
When a medication is not given exactly as it was meant to be.

Examples:
- Medicine given in the incorrect amount
- An allergic reaction to medicine

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think a medication problem occurred or was stopped before occurring?</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Medication problems that occurred:
(Click the icon on the right to add.)

Medication problems that were stopped before occurring:
(Click the icon on the right to add.)

If any other medication problems occurred which were not listed above, or if you would like to provide more information on one you observed, please list the details here:

Was staff aware of this problem or concern?

If you discussed this problem or concern with staff, did the discussion meet your needs?

Did you or your family receive an apology from staff?

If you think staff could do anything to prevent this from happening to patients, please select from the list:
Identification by families of pediatric adverse events and near misses overlooked by health care providers

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• Single ward – families who were admitted for at least 24 hours, weekdays
• 639 families were approached to participate
• 544 enrolled
• Describe the types of event
• Assessment of the institutional awareness and response (apology)
• Anonymous
• Two uninvolved clinical experts evaluated:
  – Degree of harm
  – Likelihood of recurrence
  – Quality of information in the report

• The agreement between clinical experts
Events that Families and HCP Report

- 37% of families mentioned one of more adverse events or near misses (321 events in total)
- 48% deemed to represent a legitimate PS concern
- Only 8 events were reported by HCP to the PSLS
Apologies

• Apologies 139 total
  – medication 24%,
  – equipment 16%,
  – Miscommunication
    • staff 24%,
    • staff and family 13%
“Nurse hung bag of meds for IV that my daughter was allergic to, despite the large sign on the door and allergy warning on her bracelet.”

“Suction equipment in room was re-assembled incorrectly after being emptied. This led to an accumulation of fluid in the patient.”
• HCP and family members have differing views of adverse events.
• Families reported miscommunication with and between staff most frequently, whereas staff rarely reported such events.
• 62% - identified themselves and volunteered to be contacted for future safety improvement efforts
Typology of Family Reports

![Bar chart showing the distribution of family reports by category. Categories include Medication Problems, Equipment Problems, Complications of Care, Miscommunication Between Staff, Miscommunication Between Family and Staff, and Other. The chart indicates that Miscommunication Between Staff is the most frequent category, followed by Medication Problems and Equipment Problems.]
• Results similar to other studies
• Poor communication
• Medication safety
• % insignificant events

• Reporting rates vary with the methodology
  – eg trigger tools and discharge abstract reviews
Patients and families as safety experts

Charles Vincent PhD, Rachel Davis PhD

See related research article by Daniels and colleagues on page 29 and at www.cmaj.ca/lookup/doi/10.1503/cmaj.110393
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Paying close attention to patients’ and families’ experience of care and their reports of safety issues may be the best early warning system we have for detecting the point at which poor care deteriorates into care that is clearly dangerous.
Key Points:

- Patients can provide timely and important information about the safety of care.
- When questioned, patients report safety incidents that would otherwise go undetected.
- Patients are highly motivated to report errors or problems in their care.