Patient Preference for Outcomes in Critical Care Studies

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Scientific Director, TVN
Conflicts of Interest

• Scientific Director of TVN
  – National Centres of Excellence Network focused on improving the care of seriously ill, frail elderly.
Outline

• Review concept of Integrated Knowledge Translation
• Review what is known about patient/family engagement in Research
• Review OPTICS Program of Research
• Preliminary Results from surveys of citizens.
• CIHR defines Integrated Knowledge Translation (iKT) as the involvement of stakeholders or potential research knowledge users (decision makers, patients etc.) in the entire research process.

• Each stage in the research process is viewed as an opportunity for significant collaboration with knowledge users,
  – the development or refinement of the research questions,
  – selection of the methodology,
  – data collection and tools development,
  – selection of outcome measures,
  – interpretation of the findings,
  – dissemination of the results.
• The central premise of iKT is that the involvement of knowledge users as equal partners alongside researchers will lead to research that is more relevant, more likely to be useful and more likely to be utilized by knowledge users.
• Increasing push by funding agencies

• Many granting agencies require the involvement of knowledge users, mostly decision makers

• Although intuitive and makes sense, it has not been studied well
  – Very little evaluation of the process?
  – Is it value added? What works and what does not?
• Patient involvement in the research process is also a form of Integrated Knowledge Translation
  • Less common

• Reported for the study of mental health interventions/programs, eating disorders, weight loss, health care delivery and chronic disease management such as rheumatoid arthritis, osteoarthritis
iKT - the evidence

• Very little evaluation of the involvement of patient or citizens to the research process
  • How should it be done?
  • Is it useful? Both from the perspective of the patient and researcher?
  • How to pick? How many? What role?

• Critical Care poses specific challenges
  – Not a single disease
  – Complex course of illness
  – Multiple possible outcomes
Potential Involvement of Patients/Citizens in Conduct of Critical Care Research

1. Conduct of Individual Trials
   • Steering committees

2. Management of Research Networks
   • TVN as an example

3. Setting of Research Priorities/Questions
   • Kidney Disease as an example

4. Evaluation of Research
   • Priorities of outcomes or which outcomes we use to evaluate research efforts.

5. Implementation of Research Results
   • Dissemination or “end of grant KT”
1. TVN as an example
   - National NCE funded not-for-profit network centered on improving the care of seriously ill, frail elderly

Patient/Citizen Engagement at all levels of the network
   - Representation on Board
   - Representation on all TVN committees including Research Management, Scientific Review, Education, KT committees
   - All grants, proposals must have patient engagement
   - Patients involved in the review of all grant, funding decisions
2. Kidney disease as an example

Enhanced communication, dialysis modality options, itching, dietary restrictions, depression, vascular access...
What is OPTICS?

• Program of research that centers around the integration of outcome preferences of elderly patients, lay citizens, clinician/researchers, and policy/decision-makers in critical care research.
1. Traditionally mortality has been used as the main outcome for critical care trials
   • Easy to measure
   • Increasing focus on outcomes longer time frames

2. Other outcomes
   • Organ dysfunction:
     – Cardiac, Renal, CNS, Pulmonary
   • Duration of ICU stay, hospitalization
   • Health Economic Outcomes
   • Functional Outcomes
   • Quality of Life
Need to Study Outcome Preferences

• Potential scenarios for outcomes:
  – Mortality, organ failure (CVA, Renal failure), QoL all go in the same direction → 😊
  
  – Mortality one direction, long term disability in the other e.g. Increased survival but increased stroke in survivors vs. decreased survival with less chance of stroke
  
  – Mortality unchanged but different directions for complications (CVA vs. RF).
OPTICS – Study Objectives

• To determine the preferences of elderly patients, citizens, decision-makers and researchers for
  – Outcome assessment in critical care research.

• To determine if there are significant differences in preferences for outcomes between elderly patients, citizens, decision-makers and researchers.
OPTICS - Participants

• Comparison of outcome preferences in four groups of elderly patients (defined as being over the age of 65):

1. Citizens – No critical care admissions
2. Patients - ICU survivors;
3. Decision-makers who have a role in guiding the health care system;
4. ICU Clinicians and Critical Care Researchers
Survey developed
Survey to be distributed to clinicians, health care researchers and decision makers in the new year.
Currently recruiting patients and citizens.
Patients:
- Survivors of critical Illness.
- Admission to ICU for treatment and not just monitoring
- Participants in previous ICU trials
OPTICS - Progress

• Citizens
  • Recruited by advertising in newspapers, bulletin boards, outpatient clinics
  • Eligible if over the age of 65 and no recent ICU admission
  • Invited to a meeting
    » Critical care introduced and explained
    » Need for critical care research
    » Concept of outcomes in trials
    » Asked to fill out survey with study staff present to answer questions
• First focus group of 34 participants held.
### OPTICS – Citizen characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N = 31</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>All over age 65</td>
</tr>
<tr>
<td><strong>Chronic Health Conditions: mean(SD)</strong></td>
<td>1.5 (1.4)</td>
</tr>
<tr>
<td><strong>Hospitalized in past year : n(%)</strong></td>
<td>5 (16%)</td>
</tr>
<tr>
<td><strong>Highest level of education</strong></td>
<td></td>
</tr>
<tr>
<td>High School n(%)</td>
<td>6 (19%)</td>
</tr>
<tr>
<td>Some college/University n(%)</td>
<td>6 (19%)</td>
</tr>
<tr>
<td>College/University n(%)</td>
<td>12 (39%)</td>
</tr>
<tr>
<td>Graduate n(%)</td>
<td>7 (23%)</td>
</tr>
</tbody>
</table>
### OPTICS – List of Potential Outcomes

<table>
<thead>
<tr>
<th>Potential Study Outcomes</th>
<th>Ranking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration of hospitalization</td>
<td></td>
</tr>
<tr>
<td>Risk of suffering a stroke (potentially resulting in long-term disability)</td>
<td></td>
</tr>
<tr>
<td>Risk of suffering kidney failure and being on long-term dialysis</td>
<td></td>
</tr>
<tr>
<td>Risk of long-term physical disability with ability to return to independent living at home</td>
<td></td>
</tr>
<tr>
<td>Risk of long-term physical disability with need for long-term institutional care eg., nursing home, long-term care facility</td>
<td></td>
</tr>
<tr>
<td>Return to your previous quality of life</td>
<td></td>
</tr>
<tr>
<td>Risk of having a heart attack (damage to the heart muscle with reduced heart function)</td>
<td></td>
</tr>
<tr>
<td>Risk of delirium (temporary confusion and decreased mental function)</td>
<td></td>
</tr>
<tr>
<td>Risk of permanent brain dysfunction or permanent loss of brain function</td>
<td></td>
</tr>
<tr>
<td>Risk of dying after a short illness</td>
<td></td>
</tr>
<tr>
<td>Risk of dying after a prolonged illness</td>
<td></td>
</tr>
</tbody>
</table>
OPTICS – Results

Mortality

Mortality During Acute Illness

Mortality after a Prolonged Illness

n = 30
OPTICS – Results

Quality of Life

<table>
<thead>
<tr>
<th>Rank (1 - 11)</th>
<th>Most Important</th>
<th>Least Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>45%</td>
<td>0%</td>
</tr>
<tr>
<td>2</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>3</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>4</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>5</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>6</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>7</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>8</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>9</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>10</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>11</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>
OPTICS – Results

Permanent Brain Dysfunction

- 35% at Rank 1
- 30% at Rank 2
- 25% at Rank 3
- 20% at Rank 4
- 15% at Rank 5
- 10% at Rank 6
- 5% at Rank 7
- 0% at Ranks 8-11

Risk of Myocardial Infarction

- 20% at Rank 1
- 18% at Rank 2
- 16% at Rank 3
- 14% at Rank 4
- 12% at Rank 5
- 10% at Rank 6
- 8% at Rank 7
- 6% at Rank 8
- 4% at Rank 9
- 2% at Rank 10
- 0% at Rank 11

Long Term Disability Requiring Institutional Care

- 25% at Rank 1
- 20% at Rank 2
- 15% at Rank 3
- 10% at Rank 4
- 5% at Rank 5
- 0% at Ranks 6-11

Occurrence of Delirium

- 35% at Rank 1
- 30% at Rank 2
- 25% at Rank 3
- 20% at Rank 4
- 15% at Rank 5
- 10% at Rank 6
- 5% at Rank 7
- 0% at Ranks 8-11

- Most Important
- Least Important
OPTICS – Results

Duration of Hospitalization

Risk of Stroke

Risk of Renal Failure Requiring Dialysis

Permanent Disability but able to return to Independent Living
• Outcomes ranked in top 3
  • Permanent Brain Dysfunction
  • Quality of Life
  • Long Term Disability requiring Institutional Care

• Outcomes ranked in bottom 3
  • Duration of Hospitalization
  • Risk of Dying after Prolonged Illness
  • Risk of Delirium
### OPTICS- Results

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Median (Range)</th>
<th>Mean (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Risk of physical disability with need for long-term institutional care eg., nursing home, long-term care facility?</td>
<td>1 (1,7)</td>
<td>1.9 (0.6)</td>
</tr>
<tr>
<td>2. Risk of permanent brain dysfunction or permanent loss of brain function?</td>
<td>1 (1,7)</td>
<td>2.0 (0.7)</td>
</tr>
<tr>
<td>3. Ability to return to your previous quality of life?</td>
<td>1 (1,7)</td>
<td>2.5 (0.8)</td>
</tr>
<tr>
<td>4. Risk of suffering a stroke (potentially resulting in long-term disability)?</td>
<td>2 (1,7)</td>
<td>2.4 (0.7)</td>
</tr>
<tr>
<td>5. Risk of having a heart attack (damage to the heart muscle with reduced heart function)?</td>
<td>3 (1,6)</td>
<td>3.1 (0.6)</td>
</tr>
<tr>
<td>6. Risk of suffering kidney failure and being on long-term dialysis?</td>
<td>3 (1,7)</td>
<td>3.1 (0.7)</td>
</tr>
<tr>
<td>7. Risk of long-term physical disability whose severity is mild enough to permit independent living at home?</td>
<td>3 (1, 6)</td>
<td>3.6 (0.7)</td>
</tr>
</tbody>
</table>
### OPTICS- Results

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<th>Outcomes</th>
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<tr>
<td>8. Risk of dying after a short illness?</td>
<td>3 (1,7)</td>
<td>3.7 (0.8)</td>
</tr>
<tr>
<td>9. Risk of delirium (temporary confusion and decreased mental function)?</td>
<td>4 (1,6)</td>
<td>3.7 (0.7)</td>
</tr>
<tr>
<td>10. Risk of dying after a prolonged illness?</td>
<td>4.5 (1,7)</td>
<td>4.5 (0.7)</td>
</tr>
<tr>
<td>11. Duration of hospitalization?</td>
<td>6 (2,7)</td>
<td>5.8 (0.6)</td>
</tr>
</tbody>
</table>
• Question:
Would you be willing to receive a treatment which may increase the risk of dying during the acute illness but could increase quality of life in survivors?

Yes: 24/27 (89%)

No: 3/27 (11%)
OPTICS: Next Steps

• Continue to recruit citizens in three different cities:
  • Kingston
  • Sherbrooke
  • Toronto

• Qualitative study of participants to gain insight as to preferences
Conclusion

• Integrated Knowledge Translation and patient involvement in research is rapidly expanding

• Further research is required and field is in its infancy in critical care

• Measures for the efficacy of treatments need to be reviewed from a consumer or patient point of view
  • Traditional outcomes may not be what citizens prefer
Thank You

Questions?