Who decides?

The ethics of resource allocation at the bedside

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Scenario

• 3 Children on ECMO: occupy almost all the senior ECMO-trained nurses
• Severely ill child having a liver transplant: likely to be very ill and unstable in PICU
• No more senior nurses available
• Call from another hospital
• 5 year old girl with respiratory failure: likely to die without ECMO

Who should decide whether to offer ECMO to this child?
Who *should* decide whether to offer ECMO to this child?

- Hospital administrator?
- Health Department official?
- The Health Minister?
- An ethics Committee?
- A PICU nurse who is responsible for nursing care of all the PICU patients?
- A PICU doctor who is responsible for medical care of all the PICU patients?
- Some other sort of nurse or doctor?
Spending on health by Australian Governments

• 19% of total expenditure and 9.1% of GDP in 2013-14
• Increased by 76% in real terms between 2002-3 and 2013-14
• Health spending per head of population increased 3% per year since 2005

• Cost of 1 patient day in PICU, RCH Melbourne was $9,400 in 2013-14
• Health care overall is a finite resource for which the demand is infinite
• No country can afford to satisfy every demand on its healthcare services
RATIONING MEANS A FAIR SHARE FOR ALL OF US
Healthcare resource rationing

- **Rationing**: Allocating a fixed allowance of a commodity in times of scarcity
- **Priority setting**: “The process used to establish priorities among service categories, to ensure consistency with...identified needs”
- **Implicit rationing**: via waiting lists and working within a fixed local budget
  - Inequitable and inefficient
  - Arbitrary and subject to individual beliefs and biases
- **Explicit rationing**: via published guidelines and a fixed global budget
  - Focuses conflict and dissatisfaction
  - Politically unstable
  - No guideline is detailed enough to deal with the particulars of individual cases
What is rationed in paediatric intensive care?

• PICU bed
  • Within a hospital
  • Within a state
  • Within the country or region

• Particular treatments
  • ECMO or VAD
  • Expensive drugs
  • Organ transplants
  • Consultations (psychiatry, orthopaedics)

• Particular services (e.g. physiotherapy after hours)

• Via waiting lists
  • Operating theatre time
  • MRI
  • PICU consultant’s time
Who should do the rationing?

• A clinician (nurse or doctor) in charge of care of those patients?

• A clinician not involved in the care of those patients?

• A group (of clinicians or non-clinicians or an ethics committee)?

• Someone with responsibility for PICU resources?

• Someone with responsibility for that hospital’s resources?

• Someone with responsibility for that state’s healthcare resources?
Survey of staff, RCH Melbourne

Four scenarios:

1. All PICU beds in the state are full; another child needs PICU
2. 3 disabled and one non-disabled child need the last PICU bed
3. 3 on ECMO + 1 liver transplant and another child needs ECMO
4. 6 on VAD and another 4 present needing VAD

Select who should make the decision and give reasons

52 surveys distributed; 47 returned (90%)

• PICU consultants, nurses, registrars
• Non-PICU consultants, nurses, registrars
• Allied health practitioners
• Medical students, Hospital executives, Hospital board
Results

• 47 responses
• 40 were clinicians with responsibility for patient care

• Clinician (nurse or doctor) selected as decision-maker in 71% of cases
• Non-clinician (ethics committee, hospital admin, Health minister or Health Dept official) selected in 29%

Reasons given for the choice of decision-maker:
• Process of decision-making emphasised in 57%
• Outcome of decision-making emphasised in 43%
Reasons given for the choice of decision-maker

• Clinical grounds 37%
• Group, not individual 30%
• Overall responsibility for resources 17%
• Others:
  • Time taken
  • Responsibility for outcome
  • Pre-existing guidelines
  • Independence and objectivity
  • Recognised ethical principles
The doctor as double agent

• The doctor’s fiduciary duty to an individual patient
• The doctor patient relationship depends on trust
• But the doctor has a number of actual patients and potential patients

• The doctor as responsible citizen
• Gatekeeper of healthcare expenditure
• Practising “cost-effective medicine”
Guidelines

• Fairer (than decision by a bedside clinician) and more objective
• Transparent
• Justifiable
• Preserve patients’ (or parents’) trust in the clinician

But:

• Necessarily general in character
• Insensitive to the clinical, cultural and circumstantial details of individual cases
• Hard to implement in the individual case
• Formulation of guidelines causes dissatisfaction and conflict
• Vulnerable to political pressure
Allocation decisions by groups?

• Who should be a member of the group?
• What expertise should they have?
• Whom do they represent?
• Not immune from prejudice and individual preference
• Domination by the more powerful or vocal members
• Shared culture within the group
• Time taken to assemble the group and come to a decision
• How to deal with serious differences of opinion within the group?
• For EVERY resource allocation decision, or just for some?
The time factor

- When a child’s condition is deteriorating rapidly, minutes not hours
- Time taken to gather all necessary information
- Time to contact an independent adjudicator
- Time to assemble a group, circulate information and gain a consensus
- Allocation decisions of one kind or other arise very frequently
Involving the general public in allocation decisions

- Wiseman et al, 2003
- Interviewed 373 patients in 2 Sydney GP clinics
- Asked: whose preferences should guide resource allocation decisions
- Results:

<table>
<thead>
<tr>
<th></th>
<th>Priorities among treatments</th>
<th>Priorities among patient groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
<td>48%</td>
<td>33%</td>
</tr>
<tr>
<td>Health administrators</td>
<td>21%</td>
<td>26%</td>
</tr>
<tr>
<td>Patients and families</td>
<td>16%</td>
<td>15%</td>
</tr>
<tr>
<td>General public</td>
<td>10%</td>
<td>18%</td>
</tr>
<tr>
<td>Politicians</td>
<td>3%</td>
<td>4%</td>
</tr>
</tbody>
</table>
Conclusion

• No correct answer

Possibly:
• General guidelines but not too general to be usable
• Those guidelines should be transparent, published and defensible
• Made according to publicly-agreed ethical principles
• Clinician input into the formulation of those guidelines
• Provision for regular review and revision
• Promulgated by those in charge of the macro (i.e. the state’s) budget
• Backed up by provision of funds and other resources when needed
• Discretion for bedside clinician to make decisions within that framework
SORRY NO POTATOES