Parent's and children's participation in decision-making during hospitalisation

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Lund University was established in 1666 and is the second oldest university in Sweden.

Originally four faculties were established, including Medicine, Theology, Law, and Philosophy.

The first institution of higher learning in Scandinavia, The Franciscan Monastery, existed in Lund already during the 15th century.

41,000 undergraduate students
3,000 postgraduate students
90 educational programmes
1,000 courses

6,000 employees
(45% women)

The UN Convention on the Rights of the Child

- Children are to be respected
- The child's best interest

The best interest standard

- ”A surrogate - or proxy decision maker, must determine the highest net benefit among available options assigning different weights to interests the patient has in each option”. (Beauchamp & Childress 2001 p 102)

"identity-of-interest doctrine"

- "the interest of the third party and those of the incompetent are so close that in choosing his or her own interests the third party will choose very much as the incompetent would". (Capron, 1982)

Decisions for incompetent patients

- ability to make reasoned judgements (competence),
- adequate knowledge and information,
- emotional stability, and
- a commitment to the incompetent patient's interest that is free of conflicts of interest and free of controlling influence by others who may not act in the patient's best interest".

(Beauchamp & Childress 2001 p 154)

The value of participation

- Show respect for ability
- Promote development into autonomous decision-maker
- Promote trust and communication
- Collaboration and performance of procedures are facilitated
- Control over the situation

Theoretical concepts

- The concept of autonomy
- The concept of integrity
- Competence
- Assent, consent, and refusal

The concept of autonomy

- Personal autonomy is a morally based right to self determination and a right to be involved and make decisions that concern one's own welfare
  (Tranöy 1993, Hermerén 1996)
- Free from influence and control –
  the capacity required for intentional actions
  (Beauchamp & Childress 2001)

Autonomy in action

”To respect an autonomous agent, is at minimum, to acknowledge that person’s right to hold views, to make choices, and to take actions based on values and beliefs.

Such respect involves respectful actions, not merely a respectful attitude”

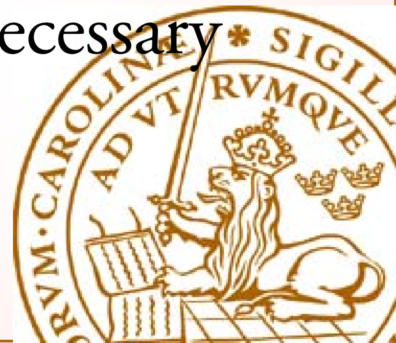
(Beauchamp & Childress 2001 p 63)

The concept of integrity

- The aim of autonomy is to protect integrity.
- Whole, unaffected, undivided, and healthy - individual and belongs to all people, from the beginning of life until its end, cannot be graded
- A characteristic

Competence

- *”The ability to perform a task”* (Beauchamp & Childress 2001 p 70)
- Criteria for competence vary, as the requirements are relative in relationship to a special task (Friedman Ross 1997)
- Can be illustrated as a continuum from full competence in a certain issue, on a certain occasion, to total inability on another occasion (Beauchamp & Childress 2001 p 72)
- When assessing individual competence it is necessary to refer to specific competence and not general competence



Assent

- *"the child's agreement to participate"*
  (Broome & Steiglitz 1992)

Children are considered to assent when they have sufficient competence to give permission of a procedure, but not enough competence to give full consent
(Foreman 1999)

Consent

- a reasoned and voluntarily acquiescence, implying that all relevant data needed to make a reasoned decision have been offered and understood
  (Koocher & De Maso 1990)

Refusal

- Competent to consent but not to refuse?

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Hallström, Runeson & Elander 2002
Runeson, Hallström, Elander & Hermerén 2002
Hallström & Elander 2004

Observations

- 9 weeks
- 24 children and their parents
- In total 135 h (r 1 h - 22 h 35 min)

Inger Hallström

Observations

- Age 5 months - 18 years
- 8 acute / 16 planned
- 15 day care / 9 hospitalised

Analysis

- Field notes
- Content analysis - manifest level
  latent level
- Three examiners

Analysis

- 137 situations included a decision process (children)
- 119 situations included a decision process (parents)
- situations were graded to the Scale of participating in decision making (Hermerén, 1996)

Grade 1

- A (where A is a member of the staff and B is the child or the parent) does not listen to B's opinions, wishes, and valuations

Grade 2

- A listens but refuses to discuss the opinions of B with B; no consultation,
  no two-way communication exists

Grade 3

- A communicates with B but does not care about B's answer; B's opinions, wishes, and valuations do not influence A's action

Grade 4

- A cares about what B says but acts only partly in accordance with B’s opinions, wishes, and valuations

Grade 5

- A acts in accordance with B’s opinions, wishes, and valuations

Grade 1

- A (where A is a member of the staff and B is the parent or the child) does not listen to B's opinions, wishes, and valuations

  Children - 10 situations

  Parents - 32 situations

Grade 2

- A listens but refuses to discuss the opinions with B; no consultation,
  no two-way communication exists

  Children - 11 situations
  Parents - 5 situations

Grade 3

- A communicates with B but does not care about B's answer; B's opinions, wishes, and valuations do not influence A's action

  Children - 51 situations
  Parents - 21 situations

Grade 4

- A cares about what B says but acts only partly in accordance with B's opinions, wishes, and valuations.

  Children - 17 situations
  Parents - 14 situations

Grade 5

- A acts in accordance with B's opinions, wishes, and valuations

Children - 48 situations
Parents - 47 situations

Numbers of optimal and not optimal participation situations at each level

Level	Optimal	Not optimal	Total (n= 137)
1	0	10	10
2	0	11	11
3	32	19	51
4	11	6	17
5	48	0	48

Factors influencing participation

- How explicitly the need was expressed
- How sensitive staff were in identifying the need

Clinical practice

- By giving parents information and education about postoperative care,
- and to invite them to participate in care, and decisions concerning care
- the goal was to facilitate the child's recovery and minimise family disruption

Routine care

- Seen as out-patients by the surgeon
- Receive a booklet by mail
- On admission, weighed, measured, and examined by the surgeon
- Receive EMLA - cream
- Preparatory booklet with photographs
- Premedication
- Parents allowed to stay until the child is fully asleep

Discharge

- when the child and parent thought it appropriate as soon as
- the child was awaken after anaesthesia
- had drunk or eaten something
- could walk with help when appropriate

Results

- Started to drink earlier
- Mobilised earlier
- Less pain
- Fewer vomited
- Shorter hospital stay