

Informed Consent in Developing Countries

Trend toward "saving the best"

- "institution of trust is morally undermined and loses effectiveness in such a sensitive area as the biomedical practices" (Kottow 566)
- "agents damage their moral self esteem and risk presenting an increasingly soiled image of their own moral stance" (ibid.)

Aspirational vs. pragmatic ethics

- Aspirational (closer to ideal) required in developed countries (less vulnerability)
- Pragmatic (far from ideal) required in developing countries (significant vulnerability)

Fabrizio/Leach standard for disclosure

- All information that could affect the patient/subject, including anticipated future interests

How Much Information is Too Much?

Yonkers Health Center vs. the media

- Time consuming, impractical to demand of physician/researcher
- Problem of overloading patient with information
- But is it necessary for respecting free of consenting decision-making?

Contextual approach to informed consent

- Will depend upon the particular patient's life plans and values (..) and level of knowledge" (Dwork 147)
- National vs. autonomous decision
- Decision can be "one's own" without being adequately informed and vice versa

Standards of Disclosure

Professional practice standards

- Based on customary practices within professional community
- Problem: biases & poor standards can be perpetuated

Reasonable person standards

- What hypothetical reasonable patient/subject would need to know
- Problem: lack of clarity on "reasonable person" - subject to cultural biases

Subjective personal standards

- Tailored to specific needs of individual patient/subject
- Problem: Highly demanding, assumes transparency of life plans and knowledge needs



Respect for Autonomy in Practice

Autonomy & Health (Fall 2012)

Beyond Informed Consent

Practice of care

- "involves particular acts of caring and a general 'habit of mind' to care that should inform all aspects of a practitioner's moral life" (Toronto, qtd. in Strahlkamp 106)
- Requires creative problem-solving on the part of care-givers

Autonomy as embedded

- Autonomy is practiced and performed in daily activities
- Depend on material and organizational context of care
- Example: which food and eating options are available to someone in a situation of complex dependency on others

Discussion Questions

- Do you think respect for autonomy comes apart at the theoretical and policy levels?
- Should patients be given unlimited access to information about treatment or a research protocol?
- What are the benefits and drawbacks of Kottow's proposed standard for disclosure?
- If we view autonomy as embedded and embedded in daily living, what are the implications for the obligations of care-givers and researchers?

Informed Consent in Developing Countries

Trend toward "sliding the bar":

- "institution of trust is morally undermined and loses effectiveness in such a sensitive area as the biomedical practices" (Kottow 566)
- "agents damage their moral self esteem and risk presenting an increasingly soiled image of their own moral stance" (ibid.)

Aspirational vs. pragmatic ethics:

- Aspirational (closer to ideal) required in developed countries (less vulnerability)
- Pragmatic (far from ideal) required in developing countries (significant vulnerability)

Fair, individualized standard for disclosure:

- All information that could affect the patient/subject, including anticipated future interests

How Much Information Is Too Much?

What's the burden of disclosure to the viewer?

- Time consuming, impractical to demand of physician/researcher
- Problem of overloading patient with information
- But not necessary for respecting free of constrained decision-making!

Personal vs. professional decision-making?

- Well depend upon the particular patient's life plans and values (...)
- and level of knowledge (Dworkin 147)

- Rational vs. autonomous decision
- Decision can be "one's own" without being adequately informed and vice versa

Beyond Informed Consent

Practice of care:

- "involves particular acts of caring and a general aspect of a practitioner's moral life" (Tronto, qtd. in Struhlkamp 106)
- Requires creative problem-solving on the part of care-givers

Autonomy as embedded:

- Autonomy is practiced and performed in daily activities
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Standards of Disclosure

Professional ethical standards:

- Based on customary practices within professional community
- Problem: biases & poor standards can be perpetuated

Reasonable person standard:

- What hypothetical reasonable patient/subject would need to know
- Problem: lack of clarity on "reasonable person" - subject to cultural biases

Subjective personal standard:

- Tailored to specific needs of individual patient/subject
- Problem: Highly demanding, assumes transparency of life plans and knowledge needs

Discussion Questions

- Do you think respect for autonomy comes apart at the theoretical and policy levels?
- Should patients be given unlimited access to information about treatment or a research protocol?
- What are the benefits and drawbacks of Kottow's proposed standard for disclosure?
- If we view autonomy as embodied and embedded in daily living, what are the implications for the obligations of care-givers and researchers?



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aspects of a practitioner
in Struhkamp 106)
• Requires creative problem
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Autonomy as embodied

- Autonomy is practiced in activities
- Depend on material and of care
- Example: which food and available to someone in a dependency on others

- Do you ... apart at
- Should patient information protocol?
- What are the Kottow's pro
- If we view au embedded in implications for and researche

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... free (of constraints) decision-
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Standards of Disclosure

Professional practice standard

- Based on customary practices within professional community
- Problem: biases & poor standards can be perpetuated

Reasonable person standard

- What hypothetical reasonable patient/subject would need to know
- Problem: lack of clarity on "reasonable person"-- subject to cultural biases

Subjective personal standard

- Tailored to specific needs of individual patient/subject
- Problem: Highly demanding, assumes transparency of life plans and knowledge needs

How Much Information Is Too Much?

Whatever the patient/subject wants to know?

- Time-consuming, impractical to demand of physician/researcher
- Problem of overloading patient with information
- But is it necessary for respecting free (of constraints) decision-making?

Only what is sufficient for rational decision-making?

- "will depend upon the particular patient's life plans and values [...] and level of knowledge" (Strong 197)
- Rational vs. autonomous decision
 - Decision can be "one's own" without being adequately informed and vice versa

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Trend toward "shading the truth"

- "institution of trust is morally undermined and loses effectiveness in such a sensitive area as the biomedical practices" (Kottow 566)
- "agents damage their moral self esteem and risk presenting an increasingly soiled image of their own moral stance" (ibid.)

Aspirational vs. pragmatic ethics

- Aspirational (closer to ideal) required in developed countries (less vulnerability)
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Pathic/proleptic standard for disclosure

- All information that could affect the patient/subject, including anticipated future interests

Beyond Informed Consent

Practice of care

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- Requires creative problem-solving on the part of care-givers

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How Much Information Is Too Much?

- Shelley: "Whether making them too much?"
- Time-consuming, impractical to demand of physician/researcher
 - Problem of overloading patient with information
 - But is it necessary for requesting free (of constraints) decision-making?

Overwhelmed patient for their decision-making?

- "will depend upon the particular patient's life plans and values (..) and level of knowledge" (Strong, 1971)
- "patients vs. autonomous decision"
- "Decision can be 'taken over' without being adequately informed and vice versa"

Standards of Disclosure

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Reasonable person standard

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Subjective personal standard

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 - "agents damage their moral self esteem and risk presenting an increasingly soiled image of their own moral stance" (ibid.)

Aspirational vs. pragmatic ethics

- Aspirational (closer to ideal) required in developed countries (less vulnerability)
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Retrospective standard for disclosure

- All information that could affect the patient/subject, including anticipated future interests



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