

Challenges for Empirical Study of Patient Autonomy, Self-determination and Co-Decision Making

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Expansion of Empirical Autonomy Research

Growing body of work claiming to empirically study patient autonomy, self-determination and co-decision making as a basis for assessing quality of care based on ethical ideals.

Munthe, C et al. (2011). Person Centred Care and Shared Decision Making: Implications for Ethics, Public Health and Research. *Health Care Analysis*, 19, online first, DOI: 10.1007/s10728-011-0183-y.

- Impact of ideas about autonomy and/or self-determination as an ethically motivated quality indicator in health care, beyond traditional ethical restriction of respect
- Fuelled by recent trends of patient/person/consumer/family centered care, clinician-patient partnership, shared decision making, personalized health care, etc.
- Increasingly carried out by investigators lacking basic knowledge of the ethical theoretical basis (care science, psychology, etc.)
- Adds further layers to the complexity of the validity and methodology of empirical bioethics.

Ashcroft RE (2003). Constructing empirical bioethics: Foucauldian reflections on the empirical turn in bioethics research. *Health Care Analysis*, 11: 3-13.

Dunn M et al (2009). Methodology, epistemology and empirical bioethics research: A constructive/ist commentary. *American Journal of Bioethics*, 9: 93-95.

Kon AA (2009). The role of empirical research in bioethics. *American Journal of Bioethics*, 9: 59-65.

Problem: Adequate Methods Needed

Typical methods used are directly imported from behavioral- or care science and psychology, without adjustment to concepts of autonomy, self-determination or co-decision making relevant to ethical theories.

Studies measure either *subjective experience* of autonomy, or aspects *only accidentally or partially associated* with being autonomous, acting or deciding autonomously, being self-determinant and/or cooperating in a decision making process, such as *retrospective satisfaction, experiences of control, degree of activity or compliance/adherence* in a decision making situation.

Munthe et al (2011).

Sandman, L et al (2012). Adherence, Shared Decision-making and patient autonomy. *Medicine, Health Care & Philosophy*, 15 (2) s. 115-127.

A person's degree of autonomy, self-direction, self-determination, or cooperation in decision-making to this effect – *in the sense that is ascribed value or ethical significance* – depends on a complex matrix of facts and relations about a person, his mind and actions that goes beyond whatever may subjectively appear to a person, or its various individual parts or typical causes or indicators.

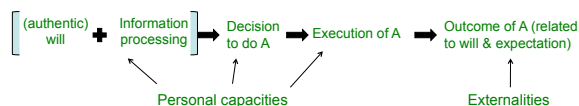
Sandman, L & Munthe, C (2009). Shared Decision Making and Patient Autonomy. *Theoretical Medicine and Bioethics*, 30 (4): 289-310.

What methodological approach could overcome this conceptual gap, so that what is measured is also what is valued in bioethical ideals focusing on autonomy?

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Two Strategies Based on Ethical Theory



Juth, N (2005). Genetic Information Values and Rights. Gothenburg: Acta Universitatis Gothoburgensis.

Sandman & Munthe (2009)

Tännsjö, T (1999). Coercive Care. London: Routledge.

Direct: measure the components and relations involved using adequate methods for each part and analytically synthesize the total result related to relevant ethical theories.

- Requires 'super-methodology' w. several methods for data-collection, measurement and analysis brought together, mixing qualitative and quantitative approaches in final analysis
- Complicated and difficult to validate reliability & validity
- If successful, high validity from an ethics standpoint, but probably weak reliability
- Awaits development and testing.

Indirect: Analytically link (parts of) the autonomy concept to indicators that are easier to measure, e.g., generic decision models (Sandman & Munthe 2009)

- Requires methodology looking at *communication- and interaction-patterns in decision making situations* involving health care professional and patient (socio-linguistics, dialogue- and decision research).
- Easier to validate reliability, validity dependent on *a priori* reasoning
- Validity less certain, but reliability potential is good
- Currently tested in the GPCC project *Organizing Person Centred Care in Pediatric Diabetes: Communication, Decision-making, Ethics and Health*

Both strategies require independent validation. Compare both + independent assessment from conceptual analysis and, e.g., deep interviews. Ideally, several studies, plus systematic review.

Strech D et al (2011). Systematic Reviews of Empirical Bioethics. *Journal of Medical Ethics*, 34: 472-477.

Core message

Studies of patient autonomy, self-determination or co-decision use inadequate methods

Ethically relevant methods need to measure more objectively factors in focus in ethical theories – directly or indirectly

New methods need validation, analytically and with reference to independent empirical data

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