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FORTE:
Forskningsrådet för hälsa, arbetsliv och välfärd

Vetenskapsrådet

QUESTIONING THE PATIENT IN PERSON CENTRED CARE: ETHICAL ASPECTS

CHILDREN, FORENSIC PSYCHIATRY, AND PUBLIC HEALTH

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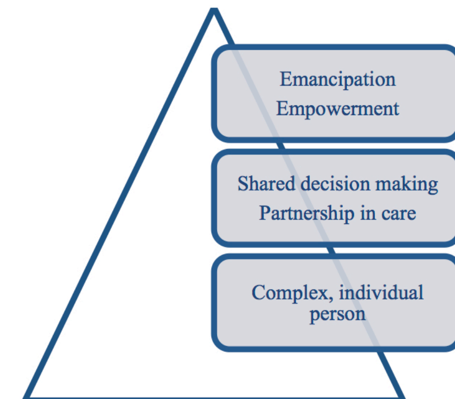
Open argumentation in SDM and PCC

- PCC: (a) ’narrative medicine’, (b) shared decision making, (c) continuity of care.
  - (b) is central: (a) serves (b), (c) feeds back to (a) and then (b), etc
  - Usualy aiming for empowerment and emancipation of patient.

El-Alti, L, et al (2017). Person Centered Care and Personalized Medicine: Irreconcilable Opposites or Potential Companions?, *Health Care Analysis*, doi: DOI: 10.1007/s10728-017-0347-5

Munthe, C, et al (2012. Person Centered Care and Shared Decision Making: Implications for Ethics, Public Health and Research. *Health Care Analysis*, 20 (3): 231-249.



- SDM: Can be understood in many ways, more or less ambitious.
  - Sandman & Munthe: 9 generic variants (widely cited and used).
  - 3 of these imply ”high-level dynamics”: mutual open argumentation where goals of care, factual assumptions, and underlying values can be questioned.

Sandman L, Munthe C (2010). Shared Decision Making, Paternalism and Patient Choice, *Health Care Analysis*, 18 (1): 60-84

Resulting issue in clinical ethics

- To what extent and how should clinicians openly question a patient's assumptions, aims and values in the course of SDM?

- Questioning as such not ethically problematic from a PCC/SDM standpoint, rather the opposite!

- *How*: in one way easy. No need to be nasty, professional responsibility to control one's own frustration. Importance of maintaining care relationship. Importance of not sliding into coercive pressure.
  - Big 'But': health care professionals usually not trained to master this.
  - Maybe abstaining from questioning is being better safe than sorry? Until they are?

- *To what extent* more tricky issue ➔ may complicate the otherwise obvious *how* issue in effect, e.g. in light of training issue.

’To what extent’ in regular clinical situations

- **Example**: patient wants to adjust drug dosage to make room for personal interests, in spite of lesser effect and increased risk of serious complications (diabetes, congestive heart failure)

- **Competent and capable adult**, who apparently prioritizes personal interests over managing biomedical health risks

- **Good clinical ethical reason to probe**, as apparent preference may easily depend on factual error, practical irrationality or be incompatible w. ethical norms. Would be irresponsible not to!
  - “Your wish and your aim may not be consistent. If you die or become severly disabled, you risk your ability to pursue personal interests even more.”
  - ”Health care has a responsibility to observe certain limits and standards, your wish transgress these”
  - Think about your friends and your family!
  - **If done well can be part of recognising the patient as an equal: a person capable of own reflection**.

- **Pragmatic complication**: patient may whish to severe the therapeutical relationship, and seek a more tractable physician.

- Sandman & Munthe (2010) generic variants
  - No. 7: Severe the therapeutic relationship ➔ the patient does as he/she pleases
  - No. 9: Agree to a strategic compromise with hope to move the patient with argument in the future.

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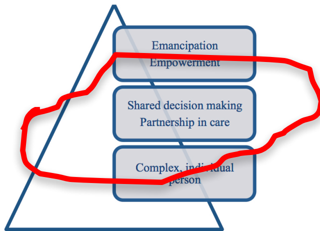
Non-standard contexts?

Forensic Psychiatry

Legally unaccountable
Undermined capacities
Coercive institutional context
Public security dominant value

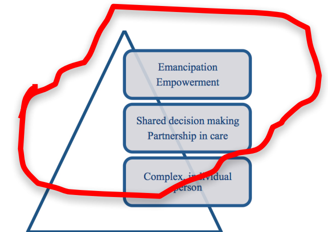
Children

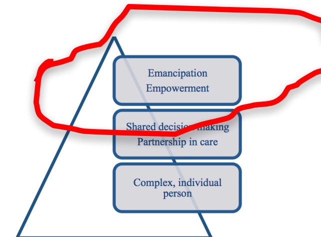
Less competent
Less capable, more vulnerable & fragile
In development towards competence and capability



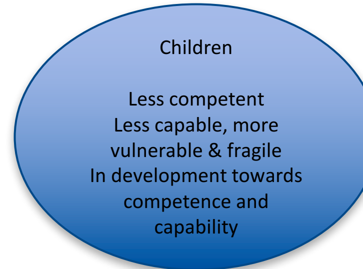
Public Health

Social, collective values
Emancipation & em-powerment not given
Collective action problems
Coercive context: communicable disease, drug resistance





Questioning children



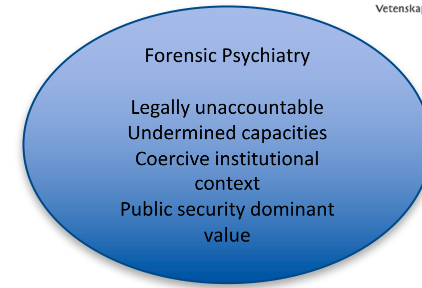
- PCC & SDM for children known to introduce challenges, and also ethically controversial.
- If PCC/SDM at all, it needs to consider long term effect on development. Interesting case: teenagers.

  Herlitz, A, et al (2016). The Counselling, Self-care, Adherence Approach to Person-centred Care and Shared Decision-making: moral psychology, executive autonomy and ethics in multi-dimensional care decisions. *Health Communication*, 31 (8): 964-973

- Pro: Teenagers have less developed authenticity, experience & control, motivates probing and questioning.
- Risk 1: Undue questioning: A teenager may rationally embrace very different aims and values than a health care professional.
  - Leaves room for questioning ”internal” inconsistencies, and factual errors
- Risk 2: The authority position of the health professional makes questioning difficult to perform in defensible ways ➔ *how*

  Hartvigsson, T, et al. Errortrawling and Fringe Decision Competence: Ethical Hazards in Monitoring and Addressing Patient Decision Capacity in Clinical Practice, resubmitted manuscript

Questioning the criminally insane



- Surprise: growing support for PCC/SDM in forensic psychiatric care.

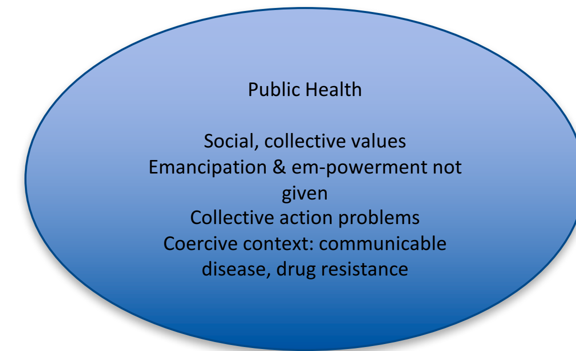
El Alti, L, et al: Ongoing study of prerequisites for PCC in this setting, incl. staff interviews regarding their perception of patient moral agency.

- Flexibility obviously constrained by prison-like context, and security considerations.
- But: Legal unaccountability of patients does not imply general incompetence.
- Basic challenge: the patients do not want to be there ➔ bad setup for PCC.

- Questioning morality of crime and norm breaches within care.
  - Pro: developing a moral perspective on others and society is part of the aim of this care.
  - Risk 1: the patient is alienated rather than empowered.
  - Risk 2: the patient is taught how to better deceive the system, frustrating the aim of the care.
  - Risk 3: may address aspects that patient is unable to relate to due to weak reasoning ability.

- Questioning pragmatics/practical rationality of non-compliance
  - Pro: care success is very much measured in compliance terms + patients want to be free.
  - Risk 1: may undermine the rationale for questioning moral reasons by stressing instrumental reason.
  - Risk 2: may address aspects that patient is unable to relate to due to weak reasoning ability.

Questioning patients for public health purposes: vaccination & drug resistance



- Persuation to vaccinate, and motivation to abstain from resistance driving drugs (antibiotics)
- Both cases: complex and sometimes disputed (incl. ”alternative”) facts
- Complicated relationship between individual and public interest
- The best interest of the individual patient not a given priority

Nijsingh, N, et al (2018). Justifying Antibiotic Resistance Interventions: Uncertainty, Precaution and Ethics. In: Jamrozki & Selgelid (eds.). *Ethics and Antimicrobial Resistance*. Dordrecht: Springer, in press.

Verweij, M & Dawson, A (2004). Ethical principles for collective immunisation programmes. *Vaccine*, 22: 3122–3126.

- Pro: opportunity to educate and straighten out misconceptions
- Pro: activating sense of due responsibility of the patient to take part in collective action
- Risk 1: Alienating the patient, undermining the care relationship
- Risk 2: Undermining trust in the institution of healthcare: the questioning makes clear that patients cannot expect their individual interest to be in focus.

Conclusion (provisional)

- **If** PCC ideal ambitiously aims for patient empowerment and emancipation …
- … **PCC/SDM in standard settings provides a strong reason for open argumentation** incl. questioning of patients' beliefs, wants and values.
- To what extent the questioning is handled well determines to what extent it may be justified.
- **Non-standard settings of PCC**, such as pediatrics, forensic psychiatry, and public health, introduce peculiar types of reasons for and against questioning patients, as well as new risks.
- **Weak patient competence** undermines reason for PCC and gives risk of counterproductivity.
- **Public health and security** considerations give risks of counterproductivity due to patient responses, and serious undermining of healthcare capacity to address problems, such as epidemics and drug resistance.
- BUT: Argumentation and questioning may also contribute to **fostering decision capacities, and a sense of moral and collective responsibility**.