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WHAT ABOUT THE FAMILY?

ETHICAL IMPLICATIONS OF FAMILY CENTRED CLINICAL DECISION MAKING

BASED ON: KIHLBOM, U & MUNTHE, C (2018). HEALTH CARE DECISIONS AND THE MORAL WEB OF FAMILY RESPONSIBILITIES. IN: LINDEMANN H, MCLAUGHLIN J, VERKERK M (EDS.), *WHERE FAMILIES AND HEALTH CARE MEET*. OXFORD: OXFORD UNIVERSITY PRESS, IN PRESS.

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Starting point: ”person centred care” (PCC)

- ”**Narrative medicine**” ➔ health professionals taking into account the totality of a patient’s life-situation, experience, preferences and values

- **Shared decision making** ➔ allowing the above to directly influence clinical decisions (more or less radically involving and shifting power to patients)

- Patient as **co-decision maker** and designer of care (rather than just someone who may veto proposals)

- Patient as **co-carer** (incidentally, as more adaption to personal circumstances and wants tends to require patients to become more involved, and for the care to take place also in the patient’s domestic setting.

Varying and conflicting reasons for PCC

1. Promoting patient autonomy

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

2. Enhancing health outcomes

Unclear if this results at all: Victor M. Montori, MD, MSc[1]; Marleen Kunneman, PhD[1,2]; Juan P. Brito, MD, MSc[1] (2017). Shared Decision Making and Improving Health CareThe Answer Is Not In. *JAMA*, 318(7):617-618. doi:10.1001/jama.2017.10168 .
http://jamanetwork.com/journals/jama/article-abstract/2648612?utm_medium=alert&utm_source=JAMALatestIssue&utm_campaign=15-08-2017

3. Promoting better adherence to treatment plans

Complex and varying idea: Sandman L, Granger BB, Ekman I, Munthe C (2012). Adherence, Shared Decision-Making and Patient Autonomy. *Medicine, Health Care and Philosophy*, 15 (2): 115-127

- **2 ≠ 3 as result of SDM may be that options with suboptimal health outcomes but better adherence potential are opted for.**

- **2 and 3 may each conflict with 1**

Assuming that patients are embedded in ”families” (in the open sense)

- As objects of patient preference and value: care as well as dislike
- As circumstance affecting treatment outcomes: case for adapting care design
- As ’engines’ of real and imagined responsibilities and relational goods
- As responsive and dynamic contexts of care implementation

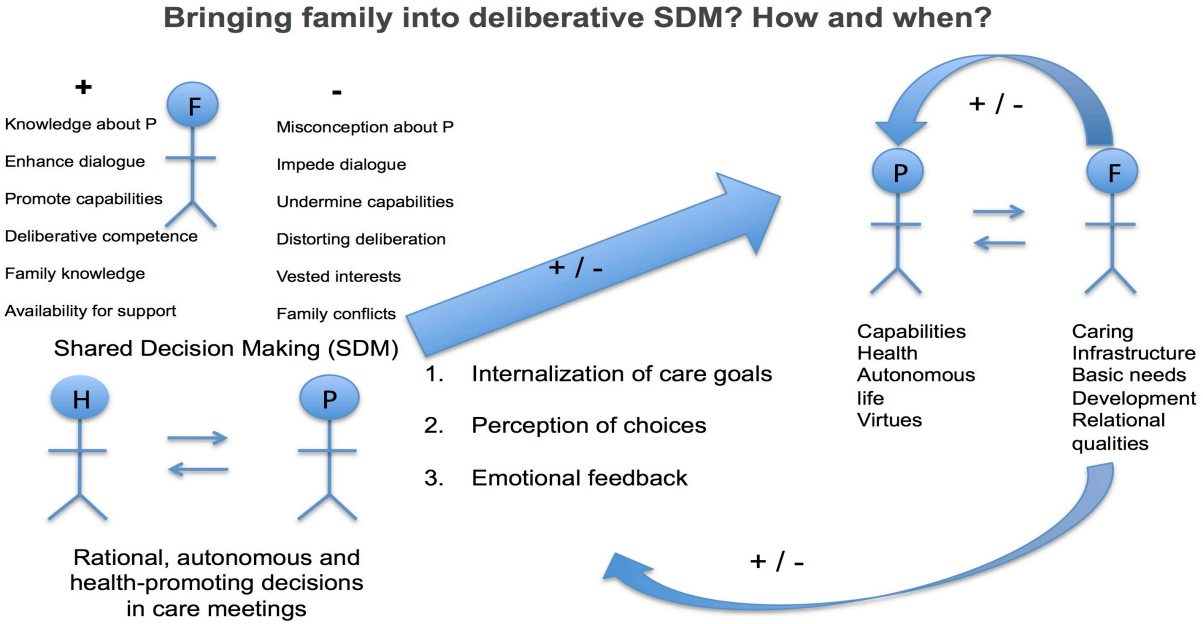
Strong reason to move from PCC to Family Centred Care (FCC), whatever reason for PCC is assumed, and however that is interpreted (eg. re. autonomy ideals)

Four Ethical Implications of Note

1. Involving family as informant and co-decision maker, how and to what extent, and why?

– The case of children and adolescent self-/home-care

Herlitz A & Munthe C (2017). Family-centeredness as Resource and Complication in Outpatient Care with Weak Adherence, Using Adolescent Diabetes Care as a Case in Point. In: Lindemann H, McLaughlin J, Verkerk M (eds.), *Where Families and Health Care Meet*. Oxford: Oxford University Press, forthcoming.



Four Ethical Implications of Note

2. Distinguishing *legitimate* care and assumed responsibility for family from *undue* exploitative/opressive adapted preferences and (merely) imagined responsibilities of patients

- Theoretically characterising the distinction in an ethically relevant way
- Recognising how to apply it in practice

- How much must the former be adaptive to the pragmatics of the latter?
- Will this necessarily introduce an element of small-scale ”ethical imperialism”?

Four Ethical Implications of Note

3. How to distribute responsibility when family is involved as co-carer?

- Prospective as well as retrospective – what underlying normative model should be applied?
- What burden is appropriate and why?
- Shared responsibilities vs. Distinct responsibilities
- Implicated HP responsibilities, eg. regarding proper education, training?
- Implications for long-term clinical priority-setting?

Sandman, L, Gustavsson, E, Munthe, C (2016). Individual Responsibility as Ground for Priority-setting in Shared Decision-making. *Journal of Medical Ethics*, 42: 653-658

Four Ethical Implications of Note

4. How much to adapt to family-internal considerations in view of the dynamic responsiveness of family contexts?

- Tension: Ethics – Pragmatics / Ideal vs. Non-ideal Normative Theory
- Taking into account judgements about the legitimacy of family-internal views and predicted responses?
- On what ground should such judgements be made by HPs and what role should that play?

Philosophically deeper issues about nature and normative status of ”family generated” webs of normative relationships and relational goods

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Thanks!

Check out our research program:

Addressing Ethical Obstacles to Person Centred Care

***http://*personcentred.se**