



# The Moral Psychology of Person Centred Adolescent Diabetes Care

**Two Potentially Conflicting Ethical Dimensions of  
Shared Decision Making for Sustainable Self-care**



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## Background: person centred care & shared decision making

- **PCC** ≈ Basing decisions regarding choice and design of care more on "narrative" information about the entirety of the patient's situation, less on preset biomedical standards that disregard individual complexity and variation
- **SDM** ≈ using the narrative in a dialogic process of deliberation to achieve a to some extent joint decision on the design of care
- Can in principle be employed to many different ends and be modelled in different ways, but there is focus on simultaneous promotion of patient autonomy and health.

More background + refs: Munthe, Sandman & Cutas (2012). Person Centred Care and Shared Decision Making: Implications for Ethics, Public Health and Research. *Health Care Analysis* 20 (3): 231-249.

- Standard model assumes highly functional, capable and, from a decision standpoint, robust patients: the paradigmatic case of "Mr. G"
- Advocated also when patients are not obviously strong or capable or duly assisted when it comes to SDM or the implementation of ensuing decisions
- Especially problematic where attempts at executing care by patients badly matches made decisions (bad *adherence*) – such as in adolescent diabetes (type 1)
- **May indicate that PCC/SDM in fact reduces autonomy, besides damaging health**

# Video study of patient consultations

Part of the cross-disciplinary project Organizing Person Centred Care in Pediatric Diabetes: Communication, Decision-making, Ethics and Health:

- Regular meetings between patients aged 13-18, (sometimes) parents and health professionals (mostly physicians), complemented by best available technology for free
- **Patients supposed to manage self-care in between:** eating, sleeping, life-style, checking blood sugar levels and determining and administering insulin dosage
- **Mismanagement bring serious long-term risks** (kidney failure around 30...), but also acute risks of seizure, coma, internal release of toxic products and so on
- **Management according to ideal regimen conflict with every day values and concerns and requires discipline, structure, memory and a systematic approach** that as a whole easily conflicts with any person's sense of being in charge of one's life
- **Adolescents manage their diabetes rather badly, but are aware of risks and facts** – at least in general terms. They most often **know what they are supposed to do**. They are not satisfied with this situation (meetings + parallel interviews).
- **Our focus:** watch for segments of dialogue that may help either explain why this is so, or provide examples for improving PCC/SDM strategies to promote adherence in self-care in accordance with patient's own considered aims, or otherwise identify and resolve ethical tensions or conflicts.

## PCC: firmly directed and inflexible, SDM: fact- and problem-oriented

- PCC very **directed by the the care prof.**: sets agenda for the patient narrative, selects what is important in it, dismisses what is not, assumes the role of "judge", dominates conversation
- SDM mainly assumes the form of a **rational problem-identification and solution-formulation process** with the care prof in the leading role, assuming a preset biomedical agenda. When patients diverge, there is often open disapproval
- **Concentration on discussing flaws** regarding the patient's conceptions, stressing preset biomedical ideal and pointing out how the patient fails to conform to it
- Solutions identified mainly with **very little room for adapting the standard self-care regimen to the patient's priorities** –and even minor faults are given attention
- Nevertheless: **patients mostly seem perfectly capable of participating, understanding and be part of a joint decision making**

# Complication: Deliberative and Habitual Decision Making

DDM involves afterthought and consideration, while HDM takes place without much preceding cognitive activity and is sensitive to momentary and unconscious influence. HDM is what we all use in our daily lives, following instinct, impulse and habit, rather than attentive deliberation with room for critical reflection. “Dual process model/theory”

## DELIBERATIVE DECISION MAKING

$$57 / 3 - 3.17 (4 + 45 / 98.234) = ?$$

Slow thinking in a controlled and adapted environment with support present and disturbances and temptations at a distance

How should I manage checking levels, eat, drink, sleep and adjust insuline dosage in various situations, given recorded past levels, levels, variations and mishaps?

## HABITUAL DECISION MAKING

Here's a person stretching out a hand,  
what do I do?

Fast thinking in regular environment with no support and disturbances and temptations ever present

How about a drink?  
Let's skip lunch and check out X!  
Can't you up some extra, so you can stay?  
Don't be a bore!

- Any self-care patient needs to be able to handle the HDM associated with managing care according to DDM: failure to align the former to the latter indicates autonomy reduction (and damages health)
- Some patients need extra support for that: vulnerable capacity for taking responsibility
- Adolescent diabetes patients seem to belong to this category

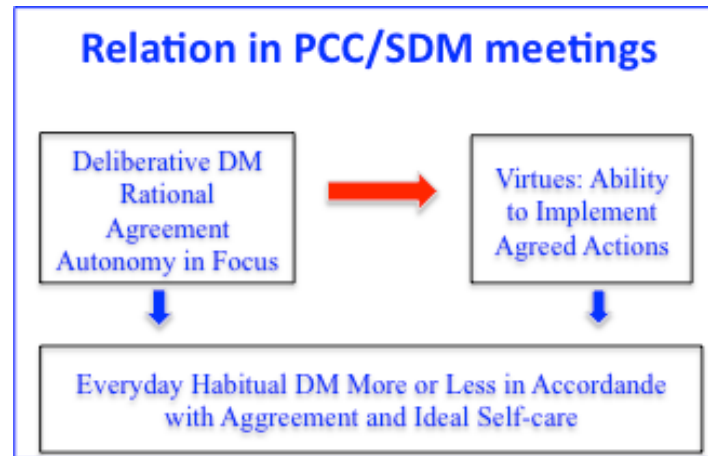
# What would be needed: the *counseling, self-care, adherence-model* of PCC/SDM

## Three Pillars of Habitual Care Decisions

- + Internalisation of care goals
- + Ability to identify significant choice situations
- + Emotional feedback mechanisms inspiring self-care according to plan

- Attention and empowering response to affective and emotional elements
- Intellectual understanding contextualised to the patients own life-situation
- Flexibility, fantasy and creativity on how self-care can be fitted into what the patient values independently of biomedical reasons: the paradigmatic example – sports, but many teens don't do or like sports
- Careful support and fostering of virtues: abilities to conform to what one would rationally prefer
- Confidence, self-efficacy/-respect, emotional resilience, sense of security

# What in fact seems to go on: Standard PCC/SDM undermines capacity for HDM & responsibility



- No apparent attention to how the PCC/SDM process affects capacity for responsibility
- **Standard PCC/SDM threatens to actively undercut this capacity:** fear, undermining of confidence, promoting of negative self-image, severed care relationship
- **Many opportunities for positive promotion of virtues are missed:** require care prof to ponder the role of health in unfamiliar activities and practices
- **Active shunning of emotional elements**, as of temporary suspending the biomedical ideal to be able to adapt what care can be had to patient's present capacity, with gradual future improvements in mind.

# Conclusions

- Success and ethics of PCC/SDM is **not only about joint clinical communication and decision making** between patients and care profs
- As soon as self-care is involved and there is a danger that the patient's capacity for taking responsibility for its management is in danger, PCC/SDM needs to attend to and be assessed also in terms of this capacity: **the counseling – self-care – adherence model**
- **Ethical aspects of PCC/SDM thus also encompasses a virtue ethical dimension** about the fostering, promoting and sustaining capacity for taking responsibility on the basis of rational and autonomous decisions, using HDM that aligns with DDM.
- Focusing only on the autonomy and rationality of DDM, **standard PCC/SDM threatens to undermine the capacity to sustain autonomy and rationality in HDM and thereby undermines development of virtues and capacity to take responsibility.**
- In practice, these two ethical dimensions therefore need balancing, and **some autonomy and rationality of DDM may need to give way, in order to promote the long-term prospect of patients' capacity to *live an autonomous life*.**
- **Conclusion may extend to other areas of practice** where people are expected to make rational and autonomous choices to be enacted in another context: credit decisions (SMS loans), purchasing potentially dangerous goods (alcohol, tobacco), other?