



Respecting the Adolescent Diabetes Patient as an Autonomous Person - What Does it Imply?

Assessing and Managing Decision Capacity for Care Decisions and Self-care

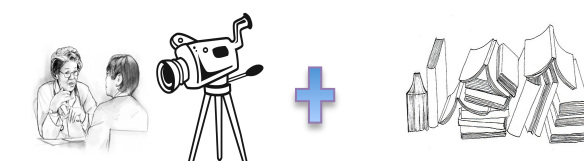
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The Problem

- Person centred diabetes care for adolescents gives freedom to decide how to execute self-care on the basis of shared decisions in hospitals, and thus leaves patients responsible for the outcome
- Assumes a robust autonomy, decision competence and capacity for responsibility that is not necessarily in place or may need to be supported
- To meet such needs and decide when the person centred approach is appropriate, assessing patient decision competence may be of help

Materials and Methods

- + Video-recordings of 12 regular consultation meetings between adolescents with diabetes and health care professionals.
- + Analysis of empirical material using theories from ethics, philosophy, psychology and the 'Grisso & Appelbaum model' of decision competence
- + Identification and categorization of performed attempts to assess decision competence and "lost opportunities" to do this
- + Analysis of potential and riskiness of strategies on the basis of theory



Autonomy & competence reducing factors

Peer- & family pressures

Momentary or entrenched emotional triggers of great force, often situational, often increased by "primers" that may counteract what the patient would prefer on calm reflection

Missing choice situations

Patients state that they often forget to measure blood sugar, take insuline

Lack of understanding of the treatment plan:

Several of the patients display failures of linking every day decisions on food, measurement and insuline dosage to their longterm treatment plan.

Not appropriately grasping risks

Patients appear to have only a vague and shallow understanding of the risk. E.g. "you can die" but not have a grasp of concrete risks (amputating a limb) or more subtle longterm consequences

Lack of appreciation or emotional engagement

Patients display understanding, but fail to discharge it in the daily management of the disease

Ideal and Reality of Person Centred Diabetes Care

Idealised situation

Two options: yes or no

One single decision

Patient can be expected to adhere to decisions made in consultation

Expected outcomes are definite and context is invaried

Non-adherence can only be explained as irrational or a failed shared decision making

Real situation

Spectrum of many possibilities of self-care styles

Many decisions in addition to planning in consultation

Adherence occur to different extents, creating a large spectrum of outcomes

Non-adherence may be due to irrationality/incapacity, but also to autonomous, rational decisions

Performed and Missed Attempts of Assessing Competence and Capacity for Responsibility

- Assessments are very unsystematic – many opportunities are missed
- Assessment styles focus on understanding and ignore non-intellectual factors
- Weak willingness to consider alternative plans or aims than biomedically predefined
- Overuse of "error thrawling" strategy that creates mostly negative emotional feedback
- Overuse of strategies of "pressing" patients to accept biomedical ideals in spite of obvious disinterest
- Lack of attention to creating appreciation and engagement in light of the disease, its nature and risks
- Some very good and positive examples to use as inspiration

Conclusions

- Systematic control of patient decision competence in diabetes care, especially for young people, can ground decisions regarding the need for action to promote capacity for autonomy and responsibility in self-care
- Actions taken to control and promote decision competence should be systematically integrated with consultation and needs to be carefully adjusted to avoid unnecessary risks or counterproductivity
- Increases probability that lack of patient adherence in terms of biomedically ideal self-care regimes are autonomously chosen by patients, and thereby less problematic from a person centred standpoint
- References, article drafts, etc available on request



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