

Organizing Person-Centred Care in Pediatric Diabetes: Communication, Decision Making, Ethics and Health

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Background

Teenagers who belong to under-privileged ethnic minority groups are often least successful in managing self-care of diabetes type 1

Effective support for self care to adolescents with diabetes demands that the care team is able to establish a dialogue with each young person that is well adjusted to their conceptions, attitudes and context.

Participants and aim of the study

The study involves two pediatric diabetes outpatient clinics in Western Sweden. One is under development and located in a residential area with many ethnic minorities

The aim of the study is to provide knowledge that may be applied to improve the organization and performance of pediatric diabetes care of teenagers with T1D and a non-Swedish background, through improved person centeredness of care

WP1. Adolescents' conceptions of risk, of the disease and of self-care

- a) Systematic literature review on adolescents risk perceptions and health behavior (health risks with delayed onset)
- b) Interviews with 12 adolescents with T1D and a non-Swedish background, regarding their disease, self-care, social situation, and the care and support from the care giving organizations
- c) Study on how the phenomena identified in a and b are mirrored and dealt with in patients consultations with their pediatric diabetologists and diabetes nurses (ongoing)

WP2. Communication between caregivers and adolescents

Study of adolescents' diabetes care meetings to acquire knowledge of the quality of communication with these patients, and to relate this knowledge to the concept of PCC.

WP4. Ethical aspects on shared decision making

Study of clinical consultations with adolescents regarding how shared decision making is applied, how patient narratives are used in the planning of the care, and to what extent ethical or other problems arise in relation to this.

WP3. Organization of care

Interviews with the care team professionals to describe and analyze their perceptions and practices regarding children with T1D, as well as the rationale of the actual organization of care, as implemented in, e.g., care meetings.

WP5. Feedback to the members of the professional diabetes team and learning from results

Develop and apply a methodology for feedback and learning from research results, in the participating pediatric diabetes teams. The methodology should:

- support the acknowledgement of identified needs;
- support the development of improved strategies with regard to communication and interaction with patients to strengthen their self-care ability;
- be of an intensity and character that is acceptable for the teams, and feasible within their available resources

Results: literature review

Demo-graphics

Age

Gender (female)

Control

Optimism bias (invulnerability)

Stereotyping

Peer influence

Sensation seeking

Achievement

Depressive mood

Close experience of negative health effect

Risk perceptions of risk behavior with long-term health consequences and delayed onset

Personality
Attitudes
Peers

SES (privileged)

Ethnicity (privileged)

Knowledge / access to knowledge

Results: Adolescent's conceptions of the disease, self-care, and care givers (1)

- The caregivers' focus on HbA1c levels created much anxiety in relation to the clinic visits, specifically among the non-adherent group. This provided much negative feedback on their ability for and success of self-care.
- The pediatric diabetologist was perceived as the major person of the team, and a long-term relationship was important.
- The nurses relieved anxiety.
- Psychologists, social workers, and dieticians were perceived to be consulted when there were *real* problems.

Results: Adolescent's conceptions of the disease, self-care, and care givers (2)

- Adolescents who had integrated their disease as part of their personal prerequisites seemed to be more successful with self-care. Helping the adolescents to reach this is then an essential task for caregivers.
- The support from significant others, ex family members, was important but improved quality of such support may help the adolescents towards integration of the disease and assuming responsibility for self-care. Care givers may aid in developing their supportive role.

Results: Ethical aspects on shared decision making (1)

- PCC, and shared decision making, realize valuable objectives, but also imply ethical issues that need to be managed in the implementation of PCC in patient consultations and care organization:
- Standard PCC models and ideals generally ignore important ethical dimensions with regard to adolescent patient's capacity to realize agreed self-care plans which are implemented outside of the structured PCC consultation situation and are crucial for long-term autonomy, adherence and health:
 - What would I want to do/wish I did, at the best of times (rational at the clinic)?
 - What is best for me right now (rational in diverse real life situations)?
 - What is rational – and acceptable - for a “person like me” (careless, incapable)?

Results: Ethical aspects on shared decision making (2)

- It is critical for adolescent diabetes PCC (for ethics and health reasons) to assess and systematically support the patient's decision competence in consultation meetings, and in the daily self-care.
- This was not performed systematically, and often in ways that imply risks of negative side-effects, e.g. decreased preparedness of patients to receive counsel, or undercut rather than promote patient decision competence through negative emotional effects, such as fear.
- A need to go from cross-examination to consultation: to listen more and tell less, invite and support the patient in the analysis of problems, empower, help patients identify and release sources of anxiety

Results: Organization

- It is not sufficient to express person-centred values in order to create a PCC process or practice;
- Facilitating long-term relationships with patients and their families is vital for the delivery of person-centered pediatric diabetes care;
- In order to empower PCC, facilitating the multi-professional team-work is highly important, as well as avoiding organizing the care according to traditional health care paradigms;
- Routines for securing a good documentation from a person-centred perspective are important.

Feedback to professional diabetes team members and learning from results

The study has designed a dialogue-based procedure for

- reflective communication between researchers and pediatric diabetes health care teams regarding study results
- reflective communication within health care teams, about research findings
- Implemented these procedures, through a number of workshops at the two participating pediatric diabetes out clinics, focusing a few themes at a time.

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**Thank you for
your attention!**