

4 Case Study

Family-Centeredness as Resource and Complication in Outpatient Care with Weak Adherence, Using Adolescent Diabetes Care as a Case in Point

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Consider two clinical situations from pediatric diabetes care.¹ In both situations, there is an adolescent diabetes patient (P), her parent (PP) and a health professional (HP) present:

1. HP: I see that your blood sugar value was a bit high here, between 12 and 14.

PP: Between 12 and 14 you say? That's bad, P! Haven't we spoken about this? It should be lower!

P: I know ...

HP: Do you know what a good value is?

PP: She does know, isn't that right, P?

P: Yes ...

PP: You need to listen to what HP says here. Your health is at stake!

2. HP: I see that your blood sugar value was a bit high here, between 12 and 14.

P: Yeah ...

PP: It was a stressful period for P. Many things were going on, you know how it can be to be a teenager.

HP: I know it can be tough, but you do know that you should try to keep the value lower?

P: Yes, I know.

PP: Maybe we can figure out a way to keep the blood value in shape also in stressful situation

¹ The cases emulate a number of concrete situations that we have observed in collaborative work with health professionals in this area.

In the first situation, we can observe that the parent does at least these three things: (i) showing off her own knowledge of the illness; (ii) placing a heavy responsibility on her child; and (iii) speaking for her child. In the second situation, we can observe that the parent takes a different attitude by: (i) helping her child with explaining the HP's observation; (ii) initiating a search for creative solutions to a difficult conflict; and (iii) letting her child speak first. In this brief report, we address how family can play both a positive and a negative role in health care of illnesses that require large amounts of outpatient care and point to some ethical questions that arise in relation to this.

Care for adolescent patients with diabetes type 1 is a recognized challenge, with known adherence problems in a context where home-/self-care and continuous vital need of day-to-day life-style adjustment. The recommended care regimen often gives rise to conflicts with broader personal and social needs and desires, and in case of weak adherence negative spirals of undermined self-confidence and/or emotional denial further deteriorating the situation may result (Boman et al. 2015; Delameter 2007; Diabetes Control and Complications Trial Study Group 1995; Herlitz et al. 2016). The need to adjust care to the specific situation is accepted within the pediatric diabetes professional community, accepting a commitment to person centeredness (Ekman et al. 2011; Luxford et al. 2010), involving alliance with the family as a critical part (Delameter 2007, Shields et al. 2006). Yet, as the two situations above illustrate, families can be involved in different ways and the issue of *how* to involve families and what ethical tensions that may actualize is largely unexplored.

Standard models of person- and family-centeredness tell us little about how to involve family members in care similar to that of diabetes. Typically, the models focus on trying to engage and educate patients and their family to decide among and

implement ready-made options, often in a hospital setting (Boman et al. 2015, Herlitz et al. 2016). These models are thus poorly equipped to address problems where, like diabetes, the illness requires large portions of self-care and life-style adjustment by patients with vulnerable decision-capacities in a mostly outpatient context (Entwistle and Watt 2013; Naik et al. 2009). We have elsewhere proposed an alternative approach more attuned to such circumstances, aiming less for rational decision-making in consultation meetings, and more at empowering patients' long-term capacities to manage their condition domestically (Herlitz et al. 2016).

This "counselling, self-care, adherence (CSA) approach" offers a look at the role that family can play to improve these types of care. We will illustrate how family members can assist in the care of teenagers with diabetes, but that there are also serious risks actualized by such involvement. In particular, we will highlight ethical complications that arise when the role of a family member is changed from "parent" to "care provider."

The CSA Approach

Successful treatment of illnesses that require substantial outpatient measures such as life-style adjustments and self-treatment actualizes decision-making both inside the clinical setting and decision-making in domestic situations. Successful treatment relies on deliberative clinical decisions that require attention, focus and time.

Treatment success, however, relies mostly on day-to-day decisions, which are mostly intuitive, not involving much conscious attention or preceded by elaborate deliberation. Regarding diabetes patients such decisions include, e.g., eating and drinking, physical exercise, use of drugs, monitoring glucose levels and adjusting daily activities. However, most of the attention of care targets only the first sort of

deliberative decisions, falsely assuming patients to automatically align their behavior to what was decided in clinical meetings with professionals. This is exemplified in both of the examples above when the health professional raises the technical issue of blood sugar values. Yet, in reality few individuals work in that way, and it is even more rare among adolescents. There is a significant difference between knowing what a good blood sugar value is and acting so that one attains a good blood sugar value.

The CSA approach is designed to address this challenge, and identifies three general and transformable elements that influence how a patient's domestic decisions align with treatment plans decided in clinical meetings, but supposed to be implemented by the patient on a day-to-day basis: *internalization of care goals*, *relevant perception of choice situations*, and *empowering emotional feedback*.

Internalized goals are located within the wider framework of the goals of a person, and are therefore less likely to give rise to conflicts. A diabetic who decides to, say, exercise more will do better if she finds a way to internalize this goal within her wider framework of independently embraced interests. For example, if she is generally interested in competing and also generally interested in spending time in nature, she can try to develop an interest for some competitive sport that takes place in nature. In this way, she will be more motivated to act in accordance with the care objective simply by pursuing the interests she already has. By raising the issue of how to find a way to have diabetes care objectives fit better with the stressful life of a teenager, the parent in the second situation above can be seen as taking a step toward improving the internalization of the care goals.

A patient's perception will have an impact on her ability to implement it in a domestic setting. An agent who spontaneously perceives cars as dangerous vehicles will be more careful when crossing a street. Likewise, a person with diabetes who

perceives jam as an unhealthy condiment with high amounts of sugar will take this into account when deciding what to spread on her toast (to the extent that the care goal of avoiding sweet food has been internalized). By developing a way of seeing the world that categorizes choice situations in a way that is relevant from a diabetes care perspective, an agent can better align her care decisions to planned treatment goals. This aspect is completely overlooked in both of the situations above, as the focus remains on the goal itself, not how its realization may be situated in the patient's daily life.

Finally, empowering emotional feedback to a person who has problems adhering to a decided care plan is important to build a confidence that things can become better. For example, a person who is constantly reminded that she fails to reach an idealized goal (say, a narrowly defined interval of HbA1c) is more likely to despair, develop an incapacitating self-image, and become less inclined to make new attempts. This is particularly relevant for adolescent, non-adherent, patients with a chronic conditions, who are in a stage of developing a more set adult identity. In the first case above, the parent can be seen as providing destructive emotional feedback that threatens to undermine a future ability to do better.

Family and the CSA Approach

Family plays an essential for the CSA approach, as its key elements are at work in domestic situations. Family can contribute relevant information beyond what is offered by patients, as illustrated in the second case above. Parents, siblings, and close friends may all be able to make less biased assessments and see more clearly how a patient reacts to stress, peer-pressure, disappointments, and so on. Family presence may serve to enhance the dialogue between caregivers and patients, for example, by

relaxing conversation, by helping to focus the discussion on topics of relevance, or to raise important issues that patients or professionals neglect.

However, when the family of the patient is brought into the clinical conversation, so will all of its dysfunctions and tensions. For each potential benefit of involving family, there is therefore a risk. In the first situation above, the parent increases the tension, while the parent in the second situation relaxes it. Parents may hold false impressions of their children and misinform professionals, their presence might intimidate the child so that dialogue is prevented, or the parents' own interests and concerns may dominate meetings while relevant issues are neglected.

Whatever (negative or positive) potential results are achieved in clinical settings may be undermined when the patient leaves the protected environment of the clinic. Family *will* influence the outcome of a CSA approach, no matter how much they are brought into or kept outside of clinical situations where care plans are decided. Family provides resources to satisfy basic needs and to support child and adolescent development, and influences what way of being and thinking is adopted by the young person, all of which contribute to the child's developing ability to handle the care. Family plays a crucial role for patients' ability to internalize health goals, to how they perceive choice situations, and a family's emotional feedback can safely be assumed to be more critical than that of health professionals. Acting on caring impulses, may easily adopt an ineffective nagging strategy instead of changing the patient's perception of everyday choices. Yet, family may just as well counteract destructive effects of, say, overly rigid health professionals, by confirming the young person's feelings, making him or her feel safe and provide emotional room for a more flexible view of how the care may be adapted. Rather than a case of all or nothing, the issue is about how and how much to involve family.

Ethical Challenges of Family Centered CSA Care

Concluding this brief case study, we set out systematically what we take to be chief *ethical* aspects of the family-related challenges mentioned.

A central challenge is for teams and professionals to achieve awareness of these aspects. We have observed that while these may take aboard the need of supporting domestic decision-making of patients, the ethical complications of family tend to be shunned as impossible to attend to, or as lying outside the clinic's organizational charter. Alas, this may make professionals less likely to address complications that they actually could do something about.

This difficulty may link to another one, namely that of possessing adequate competence to handle family-related challenges. This competence is, then, partly about *recognizing* significant ethical challenges in the clinical practice of family centered care, but also about *handling and responding* to these in an adequate way. The latter involves two elements: first, to possess the *ability of analyzing* the problems, including expected disagreements, and, second, to *implement identified solutions* successfully. Both of these offer difficulties with an ethical twist, such as the presence in the professional training of adequate knowledge and skill, the composition and organization of the clinical team, and the institutional relationship between health and social care.

There are also core professional ethical issues, and we will mention two that we have found especially emergent in our studies of adolescent diabetes care. First, there is the question of how to allocate responsibilities. This is a complex issue already when we just consider the patient and a professional. When the family aspect is taken on, it becomes immensely more so, since the family already embodies a

dense web of existing caring relations, where the interests of the patient is just one among many. In our material, we have observed how, apparently unwittingly, all responsibility is laid on the shoulders of a young patient, while parents and clinicians ally in joint resentment and disappointment over his or her performance (Hartvigsson, et al.), illustrated by the first of the cases above.

Moreover, these family relations are often central to the core value and meaning that members of the family experience in and give to their personal lives. What does it mean for the continued existence of these values to blur the line, either intentionally or merely by recognizing its inevitability, between care provider and family member? Are we stuck with a painful, albeit necessary, trade-off between preserving the values of family relations and improving health? And if so, what *is* the adequate trade-off? Or is health care licensed to intervene to change the inner relations of families for the sake of their patients' health? If so, how far does *that* license carry?²

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