CASE REPORT

Dramatic change in a young woman's perception of her diabetes and remarkable reduction in HbA1c after an individual course of Guided Self-Determination

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SUMMARY

A 24-year-old woman with type 1 diabetes participated in a randomised controlled trial proving effectiveness of a flexible Guided Self-Determination (GSD) intervention. She had for 10 years been living with a complex situation of eating disorder, poor glycaemic control, non-attendance and psychosocial distress. She managed to change her perception of diabetes dramatically and improved her glycaemic control. Considering the complexity of her case, we explored how she achieved these changes. A GSD-trained nurse delivered the intervention, which involves reflection sheets and advanced professional communication. Glycated hemoglobin was reported in the patient's record and an interview conducted by external interviewers was analysed thematically, indicating that a four-stage process of empowerment had taken place: 'focusing on life prior to numbers', 'unpacking a heavy burden', 'breaking out of isolation through communication' and 'finding strength within oneself'. The article emphasises that GSD works by breaking isolation through communication as an appropriate way to achieve good diabetes control.

BACKGROUND

Studies in younger adults with type 1 diabetes (T1D) have identified a combination of poor glycaemic control and high diabetes distress, which seems difficult to amend because of frequent non-attendance and low expectations of success both among the younger adults and their professional care givers. Research thus calls for interventions that are especially tailored to younger adults with poorly controlled T1D, applicable by clinicians in practice, and effective in promoting health and preventing complications. Women, in particular, seem to struggle with a combination of long-term poor glycaemic control, weight concern, misuse of insulin, late complications and psychosocial distress or depression.^{1–3} This was the case for our case patient, a 24-year-old woman, who was 1 of 200 younger adults 18–35 years old with T1D who took part in a real life randomised controlled trial (RCT), testing the effectiveness of a flexible version of Guided Self-Determination (GSD),⁴ prior proven effective in adult care.^{5,6}

Five hundred and three younger adults with diabetes duration ≥ 1 year and glycated hemoglobin (HbA1c) $\geq 8.0\%$ (≥ 64 mmol/mol) were invited by

letter and 289 of them were additionally informed about the intervention either at informational meetings (n=34) or in connection with usual appointments, as, for instance, the patient in our report. Two hundred of them provided consent (50% men) and were randomised 2:1 stratified for sex and age (18–26 and 27–35 years old).⁴ The 134 participants in the intervention group were offered GSD at once whereas the 66 participants in the control group continued to receive care as usual and were offered GSD 18 months after randomisation.

Nurses provided the intervention after 40 h of GSD-training,⁴ including knowledge about the theories behind GSD,^{7–9} and supervised use of GSD-reflection sheets and advanced communication skills, such as mirroring, active listening and values clarifying responses.^{10–12} Completion of the GSD-training required that the nurses pass a test and document that, as part of training, they had supported two people with diabetes in completing an individual GSD-course.

As earlier explained in detail,⁴ HbA1c was measured at baseline and every 3 months for 18 months, and a battery of psychosocial parameters were measured immediately before randomisation and again 9 and 18 months thereafter, including Problem Areas in Diabetes (PAID), WHO-5 well-being index (WHO-5), Rosenberg's Self-Esteem Scale (RSES) and three scales developed by self-determination theorists: Health Care Climate Questionnaire (HCCQ), The Treatment Self-Regulation Questionnaire (TSRQ) and the Perceived Competence in Diabetes scale (PCD).

GSD-women reduced HbA1c significantly -0.5% vs $+0.1\%$ ($p=0.017$) and benefited psychosocially according to the scales,⁴ whereas improvements among men could not be related to the intervention.⁴

Completion of the intervention was defined as having completed and discussed a central reflection sheet on "Dynamic problem-solving",¹³ which was planned for the fifth GSD session. The completers had a median of 8 (5–14) 1 h sessions; 29 of the participants required additional sessions, for a median of 11 sessions in total (9–14). The variation in the number of sessions the participants needed in order to complete was part of the flexibility and the real-life characteristics of the RCT, which were argued to mean that the GSD intervention and its results might be more easily translated into daily care.

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CASE PRESENTATION

The reported patient had a 10-year-long complex situation of an eating disorder, poor glycaemic control, non-attendance and psychosocial distress. After the GSD intervention, she changed her perception of diabetes dramatically and also improved her glycaemic control: HbA1c decreased from 92 mmol/mol to 53 mmol/mol. Her improvements in self-reported psychosocial functioning included lower psychosocial distress, higher self-esteem, higher perceived autonomy support from professionals and higher perceived competence in managing diabetes. Since her diagnosis at the age of 8, she was seen at four diabetes clinics, including Steno Diabetes Center (SDC) (table 1).

INVESTIGATIONS

Considering the patient's improvements despite the complexity of her case, and the fact that women in particular benefited from the RCT intervention,⁴ we aim to explore how she achieved the changes. A case study was conducted 1 year after she had finished the trial. She was interviewed by two external interviewers who were not involved in the intervention, with her filled-in reflection sheets supporting memory of the intervention. The interview was thematically analysed according to a procedure suggested by Braun and Clarke.¹⁴ An overview of her diabetes management from onset until after the GSD intervention was made based on the interview and electronic patient record data on HbA1c, treatment and complication status.

Finally, changes on psychometric scales, measured before and after the intervention, were included.

TREATMENT

The GSD intervention is a form of life-skills training involving the use of reflection sheets (see online supplementary material), which are filled in by the patient before a number of conversations with healthcare professionals (HCP) with advanced communication skills. GSD prompts a six-stage mutual problem-solving process: 'joining a mutual relationship with the HCP', 'self-exploration', 'self-understanding', 'shared decision making', 'action' and 'feedback from action'. Owing to the complexity of this patient's situation, she was offered extra consultations (14, compared to a median of 8 (range 5–14) for all participants). This allowed her to work on two occasions on 'Dynamic Judgement-Building' a central five-page GSD sheet inspired by Bos,¹³ which she used to reflect on two major issues related to her own reaction to diabetes: 'difficulties in integrating diabetes into my life' and 'sharing difficulties related to diabetes with my parents'.

OUTCOME AND FOLLOW-UP

The thematic analysis showed that GSD had supported the patient through an empowering process comprising four stages: 'focusing on life prior to numbers', 'unpacking a heavy burden', 'breaking out of isolation through communication' and 'finding

Table 1 The patient's life with diabetes before, during and after GSD intervention

Time	The patient's reactions and experience	Glycaemic control
1996 8 years old	She was diagnosed with diabetes at centre 1 Parents responsible for management She had a good start with diabetes and did not find it difficult to live with	She not sure about glycaemic status
2002 13–14 years old	She took over BG control herself BG deteriorated High school Little attention to diabetes She was seen at centre 2. Onset of eating disorder (anorexia)	She remembers glycaemic control to be poor but is not sure about the exact HbA1c results
2005–6 17–18 years old	She isolated herself with diabetes. People knew about her diabetes, but she avoided talking about it with parents and friends. She felt isolated and alone Eating disorder deteriorated, yet not addressed by HCPs Lowest BMI: 16 HCPs focused on numbers and gave advice concerning insulin. Not aware of the exact difficulties. 10 min is not enough time to find out	
2007–9 19–21 years old	She moved to the capital region and started studying at university She had regained weight, but was, in her own words, not 'mentally cured' She was seen at centre 3 but showed up only once Non-attendance for 2 years	
April–July 2009 21 years old	She started at centre 4, SDC. Nine normal visits with the same nurse over 4 months. She was offered a pump—refused, was not interested	HbA1c from 117 to 86 mmol/mol
August 2009– March 2010 22 years old	She had 9 months of non-attendance She turned up with her boyfriend. She was crying and asked for help She was offered a chance to take part in the GSD project, accepted this, signed informed consent form, was randomised to intervention group and chose individual GSD	HbA1c 92 mmol/mol
June 2010–March 2011 22–23 years old	She took part in eight individual visits with a GSD-trained nurse	HbA1c from 92 to 81 mmol/mol
March–Oct 2011 23–24 years old	Six extra GSD visits (in total 14) together with the GSD nurse and VZ. She started talking to a female friend and especially to her boyfriend. Finally, she talked to her parents, revealing her difficulties in living with diabetes, which she had hidden from them for 10 years	HbA1c from 81 to 68 mmol/mol
December 2011 24 years old	Two months later, she expressed a wish to become pregnant. Consequently, she was referred to the pregestational unit for advice	HbA1c 64 mmol/mol
October 2012 25 years old	Interview conducted by external interviewers	HbA1c 53 mmol/mol

BG, blood glucose; BMI, body mass index; GSD, Guided Self-Determination; HbA1c, glycated hemoglobin; HCP, healthcare professionals.

Figure 1 The patient's experience of her own reactions when receiving usual care and the Guided Self-Determination (GSD) intervention.

In usual care

Susan found that the focus was on numbers

Susan experienced her situation deadlocked

Since adolescence Susan had a pattern of eating disorder, poor glycaemic control and non-attendance

With her difficulties silenced, they became mixed up in one big mess, which Susan could not resolve

Susan did not engage other people when they asked about her diabetes. This meant that she did not receive any help from others

Being isolated with diabetes

In GSD

Susan found that focus was on her life with diabetes

Susan found it productive to spend time focusing on her life with diabetes

Using reflection sheets, Susan explored her own reactions to diabetes and became able to identify and unpack difficulties hidden away for many years

Susan broke through her isolation and 'unpacked a heavy burden' through communication

Susan opened up to significant others, sharing the unpacked difficulties, first with the GSD-nurse, secondly with her friends and boyfriend and finally with her parents

Finally Susan found the strength within herself to manage diabetes

strength within herself' (figure 1). The process of empowerment is described below.

Focusing on life beyond numbers

In the patient's previous contact with diabetes HCPs, she found that conversations focused mainly on 'numbers', which she perceived as rather unproductive (figure 1). Having filled in GSD reflection sheets before and during the conversations, she was able to express and share her difficulties with the GSD nurse. She perceived this as shifting the focus from numbers to her life with diabetes, which she saw as far more productive, especially when it came to improving glycaemic control and maintaining the motivation to attend and participate in treatments.

I wasn't being held to account anymore. It was about all my thoughts about diabetes and how it's part of my life. It was clear that that was the problem, and that's what we worked on. And when that got sorted out, the numbers followed.

For this patient, it was important that the intervention be conducted by a HCP with knowledge about diabetes. She also highlighted the importance of having enough time to start opening up about thoughts and feelings.

Unpacking a heavy burden

The patient experienced the process she had gone through as long and tough, with slow progress and many difficulties. Yet she also saw the process as an emotional accomplishment, whereby she was released from her suppressed emotions.

My God, how I've cried—it was so many years of baggage that was slowly being unpacked... and that also made me realise that change takes a really long time.

She described her diabetes during her adolescence and before participating in the project as a 'black box' or 'shadow': "Just

'argh', it was too much! It was a mix of failures, negative thoughts and bad regulation that I didn't know how to deal with."

She had isolated herself with her diabetes, not mentioning the condition when she was with her family and friends. "I hid it before, and that was a pretty big burden to carry." She realised that 'unpacking the box' took a long time. It was not *something you could do overnight*, as it involved more issues than expected, including problems that had been hidden away for many years and that were connected with the necessity of accepting diabetes as a lifelong condition.

Breaking out of isolation through communication

Describing her tendency since adolescence to hide her difficulties with diabetes from everyone, including her family, friends and boyfriend, the patient recognised that she had turned away from the people closest to her, not only isolating herself with diabetes but also missing out on much-needed support.

All my female friends and family [...] knew it, but nobody asked about it. Certainly not my friends, anyway... and if they did, they'd got fobbed off right away. I didn't want to talk about it at all.

Having initially shared these difficulties with the nurse in GSD, it was subsequently easier for the patient to share them with a female friend and her boyfriend. The most challenging hurdle was, however, to share her difficulties with her parents, though she perceived them as 'very supportive'. This was obviously due to the fact that she had given them the impression for 10 years that managing diabetes was easy for her. As part of GSD, the patient made a drawing, showing a person swimming in the sea far from the beach, to show how it felt to live with diabetes. At each conversation, drawing how close she was to the shore became a way of visualising and acknowledging her

own progress. When finally asked what she deemed necessary in order to get up on land, she clearly stated that it was telling her parents about her difficulties with diabetes. This was the basis for setting another challenge: 'sharing difficulties related to diabetes with my parents'. This seemed crucial to finally developing the courage and skills to communicate and share her difficulties connected with diabetes: "I feel like that part of me that I didn't talk about before, I'm sharing that now. I'm talking to my friends and family about it."

Finding strength within oneself

The patient's participation in the GSD project released the potential to integrate diabetes into her life and to live her life the way she wanted, while accepting the limitations imposed by her diabetes. She now recognised an inner strength in herself that she had not experienced before.

Firstly, I'm better regulated, but it's more than that. I've brought my diabetes into my life in a good way—a positive way, where I share it with other people and work with it. It's easier now. [...] Actually, I find a lot of strength in myself that I didn't have before.

However, she expressed concerns related to being transferred to the regular check-ups. She described the changes she had accomplished as 'very fragile' and described the method as 'very good, but it shouldn't just stop'.

After the intervention

Two months after end of the trial, the patient expressed the wish to become pregnant and was referred to the pre-pregnancy department. The physician, who knew her from before, wrote in her record: 'The patient has made a dramatic change in the perception of her diabetes and remarkable reduction in HbA1c'. The patient had, at that time, decreased her HbA1c to 64 mmol/mol and at the time of the interview it was reduced to 53 mmol/mol. The physician's statement corresponded well with improvements accomplished in the patient's psychosocial functioning, measured through self-reported data from baseline and again 25 months later: psychosocial distress measured on the PAID scale (0–100)¹⁵ was reduced from 64 to 21, cut-point for high distress ≥ 30 ,¹⁶ and, furthermore, her self-esteem increased from 14 to 28 on Rosenberg's-SES (0–30) with a cut-point for low self-esteem ≤ 15 . On self-determination scales without cut-points,¹⁷ she also increased her perceived competence with diabetes, PCD (1–7), from 3.4 to 6, and her perception of autonomy support from HCPs, HCCQ (1–7) from 4 to 6.8. These changes corresponded well with her answer when asked to describe the outcome of the course in one sentence. She wrote: 'I have become better at working together with—and not against—my diabetes'.

DISCUSSION

The case report patient went through an empowering process that was of great importance for her life with diabetes. We consider her improvements in HbA1c and psychosocial functioning to be connected with increased autonomy in managing diabetes,¹⁸ which involved relatively stable changes as they were integrated into her life and were consistent with self-concordance.¹⁹ Though widely acknowledged in diabetes care, empowerment has been difficult to realise in practice without using advanced methods such as GSD.⁶ The patient emphasised the importance of the GSD reflection sheets, which were also seen as important by nurses newly trained in empowerment-based work.²⁰ The work with reflection sheets is comparable to reflective writing, which likely breaks cycles of isolation in

patients, increases the humility of HCPs and provides a shared understanding of the patient's situation. Because the patient was well prepared and her words on the reflection sheets were used as a starting point for conversation, her time with the nurse was used more effectively, focusing on what was personally important for her. Through this process, both she and the GSD-nurse seemingly increased their reflective capacity.^{21 22} According to the patient, this made the sessions seem more meaningful, increasing her willingness to attend compared to previous treatments. A change from compliance to concordance is likely to have taken place.²³

An eating disorder had been part of the patient's history. Though the seriousness of this disorder had decreased with time, she was, in her own words, 'not mentally cured' at the beginning of the intervention. This phenomenon has been discussed by Balfe *et al.*²⁴ It is striking that though her eating disorder was not explicitly addressed during the intervention, it seemed to fade as she found strength within herself.

We consider the flexibility of the intervention important for this patient, offering her a high number of sessions according to her needs and allowing her to choose whether the intervention would be held in groups or individually. It could be argued that GSD interventions are time-consuming—14 1 h sessions in her case and an average of eight sessions among all the participants. In comparison, before the intervention, nine traditional outpatient visits had been offered to her over 4 months, as an extra attempt to help her, which apparently did not change her attitude to diabetes.

She appreciated that the intervention was conducted by clinicians specialising in diabetes.

The main expenditure on her GSD course was the 14 h spent with the nurse, which, however, is an insignificant expense if future diabetes complications can be avoided or delayed.²⁵ The patient had one eye laser-treated shortly after the interview.

Conclusion

The patient benefited from this flexible GSD-intervention, breaking out of her isolation by focusing on what was personally important for her and going through an empowering process with improved HbA1c and psychosocial functioning.

Learning points

- The remarkable positive outcome for the patient in this article is a good message for healthcare professionals in diabetes and other chronic care settings, who for long have asked for concrete empowering methods that they can use as an integral part of clinical care.
- Time can be used more efficiently when patients work at home to clarify their difficulties.
- The study shows the importance of shifting the focus from 'numbers' to the patient's life with diabetes.
- The article shows that a mess of unspoken difficulties and non-accepted diabetes had to be unpacked before a time-consuming integration process could start.
- The article emphasises that breaking isolation through communication is an appropriate way to achieve good diabetes control.

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