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Focusing on life beyond numbers.
Guided Self-Determination (GSD)
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Introduction
Studies in young adulthood have identified difficulties for young adult women in particular, who struggle with a combination of long term poor glycaemic control, weight concern, misuse of insulin, late complications and psychosocial distress or depression (1-3). Research thus calls for interventions which are especially tailored to young adult women with poorly controlled Type 1 Diabetes (T1D), applicable by clinicians in practice and effective in promoting health and preventing complications. Susan, a 24-year-old woman, was one of 200 patients between 18 and 35 years old with type 1 diabetes who took part in a randomised controlled trial (RCT), testing the effectiveness in this age group of a flexible version of Guided Self-Determination (GSD) prior proven effective in adult care (4,5).

Guided Self-Determination
The GSD intervention is a form of life-skills training involving the use of reflection sheets, which are filled in by the patient before a consultation with the healthcare professional (HCP). "Self-exploration", "self-understanding", "shared decision making", "action" and "feedback from action" (1, 2).

Purpose
To examine how an individual with complex chronic disease experience GEB. The case study should provide insights into how the autonomy supportive intervention is experienced, from the person perspective.

Methods
A case study was conducted one year after Susan had finished the trial. Susan was interviewed by two external interviewers HbA1c 53

Susan’s life with diabetes before, during and after GSD training

<table>
<thead>
<tr>
<th>Time</th>
<th>Susan’s reactions and experience</th>
<th>Glycaemic control</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996 8 years old</td>
<td>Early diagnosis at the age of 2; education at centre 1; parents responsible for management. Susan had a good start with diabetes and did not find it difficult to live with.</td>
<td>Susan not sure about glycaemic status.</td>
</tr>
<tr>
<td>2002 12-14 years old</td>
<td>Susan took over BG control herself; BG deteriorated. High school. Little attention to diabetes. She was seen at centre 2. Onset of eating disorder (anorexia.).</td>
<td>Susan remembers glycaemic control to be poor but is not sure about the exact HbA1c results.</td>
</tr>
<tr>
<td>2005-6 17-18 years old</td>
<td>Susan 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 minutes is not enough time to find out.</td>
<td></td>
</tr>
<tr>
<td>2007-9 19-21 years old</td>
<td>Susan moved to the capital region and started studying at university. Had regained weight, but was in her own words not ‘mentally cured’. Susan was seen at centre 3 but showed up only once. Non-attendance for two years.</td>
<td></td>
</tr>
<tr>
<td>April-July 2009 21 years old</td>
<td>Susan started at centre 4, SDC. Nine normal visits with the same nurse over four months. Susan was offered a pump – refused, was not interested. HbA1c from 117 to 86.</td>
<td></td>
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<tr>
<td>August 2009- March 2010 22 years old</td>
<td>Susan had nine months of non-attendance. Susan turned up with her boyfriend. She was crying and asked for help. Was offered a chance to take part in the GSD project. Accepted this, signed informed consent form, was randomized to intervention group and chose individual GSD. HbA1c 92</td>
<td></td>
</tr>
<tr>
<td>June 2010- March 2011 23-25 years old</td>
<td>Susan took part in eight individual visits with a GSD-trained nurse. HbA1c 85</td>
<td></td>
</tr>
<tr>
<td>March-Oct 2011 25-24 years old</td>
<td>Six extra GSD visits together with the GSD nurse and V2.</td>
<td></td>
</tr>
<tr>
<td>December 2011 24 years old</td>
<td>Two months later. Susan expressed a wish to become pregnant. Consequently she was referred to the pre-gestational unit for advice. HbA1c 80 HbA1c 68</td>
<td></td>
</tr>
<tr>
<td>October 2012 25 years old</td>
<td>Interview conducted by external interviewers HbA1c 53</td>
<td></td>
</tr>
</tbody>
</table>

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 loneliness
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.

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.

Implications for practice
We consider GSD applicable by HCPs in order to facilitate a process of change in young adults with a complex of poorly controlled T1D and psychosocial distress. Time is used more efficiently when patients work at home to clarify their difficulties. Shifting the focus from ‘numbers’ to the patients’ life with diabetes can increase attendance and release the potential for change.

Conclusion
Susan benefitted from this flexible intervention, breaking out of her isolation by focusing on what was personally important for her and going through an encompassing process with improved HbA1c and psychosocial functioning.

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References