Danish University Colleges

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 number of conversations with professionals with advanced communication skills. GSD prompts a six-stage mutual problem-solving process: ‘joining a mutual relationship with the healthcare professional (HCP)’, ‘self-exploration’, ‘self-understanding’, ‘shared decision making’, ‘action’ and ‘feedback from action’ (1, 2), and effective in promoting health and preventing complications. Susan started talking to a female friend and especially to her boyfriend. Finally she talked to her parents, revealing her difficulties in living with diabetes as a heavy burden’ through communication.

Susan broke through her isolation and ‘unpacked a big dark shadow behind her’ by unpacking difficulties hidden away for many years with her parents, secondly with her friends and boyfriend and finally with her parents.

Susan perceives diabetes as a big dark shadow placed alongside with her.

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 who were not involved in the intervention. The interview was thematically analysed according to a procedure suggested by Braun and Clarke (3). An overview of Susan’s diabetes management from onset until after the GSD intervention was made based on the interview and electronic patient record data on HbA1c, and psychosocial scales, measured before and after the treatment and complication status. Finally, changes on interview and electronic patient record data on HbA1c, until after the GSD intervention was made based on the overview of Susan’s diabetes management from onset a procedure suggested by Braun and Clarke (3).

References

In usual care
Susan found that the focus was on numbers. Susan experienced her situation stigmatized since adolescence. Susan had a pattern of eating disorder, poor glycaemic control and psychosocial distress. 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 might not be the case if Susan 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 release difficulties hidden away for many years. Susan broke through her isolation and ‘unpacked a big dark shadow behind her’ through communication.

Eventually, Susan successfully communicated her diabetes management with her parents, especially about her diabetes. This meant that she did not receive any help from others.

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 empowering process with improved HbA1c and psychosocial functioning.

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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</td>
<td>8 years old</td>
<td>Susan not sure about glycaemic status.</td>
</tr>
<tr>
<td></td>
<td>She was diagnosed at age 6 months of centre 1.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Parents responsible for management.</td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>12-14 years old</td>
<td>Susan took over BG control herself. BG deteriorated.</td>
</tr>
<tr>
<td></td>
<td>High school.</td>
<td>She was seen at centre 2. Onset of eating disorder (anorexia).</td>
</tr>
<tr>
<td>2005-6</td>
<td>17-18 years old</td>
<td>Susan isolated herself with diabetes. People leave about her diabetes, but she avoided talking about it with parents and friends. She felt isolated and alone.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Eating disorder deteriorated, yet not addressed by HCPs. Lowest BMI: 16.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>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>
</tr>
<tr>
<td>2007-9</td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Non-attendance for two years.</td>
</tr>
<tr>
<td>April-July 2009</td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HbA1c from 77 to 86.</td>
</tr>
<tr>
<td>August 2009-</td>
<td>22 years old</td>
<td>Susan had nine months of non-attendance.</td>
</tr>
<tr>
<td>March 2010</td>
<td></td>
<td>Susan turned up with her boyfriend. She was crying and asked for help.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>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.</td>
</tr>
<tr>
<td>June 2010-</td>
<td>23-25 years old</td>
<td>Six extra GSD visits together with the GSD nurse and V2.</td>
</tr>
<tr>
<td>March-Oct 201</td>
<td></td>
<td>Susan 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.</td>
</tr>
<tr>
<td>2011</td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HbA1c: 81 HbA1c: 68.</td>
</tr>
<tr>
<td>October 2012</td>
<td>25 years old</td>
<td>Interview conducted by external interviewers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HbA1c: 64</td>
</tr>
</tbody>
</table>

Questions
- Was GSD helpful for Susan in managing her diabetes and improving her psychosocial functioning? 
- How did GSD help Susan to communicate her diabetes management with her parents? 
- What were the specific difficulties Susan faced during her diabetes management? 
- How did GSD help Susan to address these difficulties? 
- What role did external interviewers play in Susan’s diabetes management? 
- What was the impact of GSD on Susan’s psychosocial functioning and glycaemic control? 
- How did GSD influence Susan’s decision-making process? 
- What was the role of HCPs in Susan’s diabetes management? 
- How did GSD help Susan to improve her communication skills?