Danish University Colleges

Focusing on life beyond numer.
Guided Self-Determination (GSD)
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**Intervention**

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).

**Purpose**

To examine how an individual with complex chronic disease experience GEB. The case study should provide insight 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 (5). 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, treatment and complication status. Finally, changes on psychometric scales, measured before and after the treatment and complication status. Finally, changes on insight into how the autonomy supportive intervention functioned.

**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>One day diabetes was diagnosed 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: 15.</td>
<td>HbA1c 85.</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.</td>
<td>Non-attendance for two years</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.</td>
<td>HbA1c from 77 to 86.</td>
</tr>
<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 randomised to intervention group and chose individual GSD.</td>
<td>HbA1c 92.</td>
</tr>
<tr>
<td>March-Oct 2011, 25-24 years old</td>
<td>Six extra GSD visits together with the GSD nurse and V2. 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 12 years.</td>
<td>HbA1c 81</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.</td>
<td>HbA1c 64.</td>
</tr>
<tr>
<td>October 2012, 25 years old</td>
<td>Interview conducted by external interviewers</td>
<td>HbA1c 53.</td>
</tr>
</tbody>
</table>

**In usual care**

Susan found that the focus was on numbers. Susan experienced her situation_developed diabetes. Since adolescence Susan had a pattern of eating disorder – poor glycaemic control and morbidity. 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 clarify 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.

**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 TID 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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**References**


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**Susan perceived diabetes as a big dark shadow behind her**

Being isolated with diabetes

Finally Susan found the strength within herself to manage diabetes

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**Susan perceives diabetes as coloured and placed alongside with her**

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