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Prip, Anne; Christiansen, Anette Wendelboe; Zoffmann, Vibeke

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Focusing on life beyond numbers
Guided Self-Determination (GSD)
Anne Prip, Anette W. Christensen, Vibeke Zoffmann
Metropolitan University College, School of Nursing, Copenhagen, Denmark

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 provider’ (HCP), setting goals, exploring barriers, generating alternatives, planning, and action. Conversations with HCPs are about life beyond numbers, to promote an ‘instead of’-focus on life with diabetes (6). It 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 treatment and complication status. Finally, changes on psychometric scales, measured before and after the intervention, were included.

References

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.

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>Sugar and diabetes at centre 1. Parents responsible for management. Susan had a good start with diabetes and did not find it difficult to live with. Susan not sure about glycaemic status.</td>
</tr>
<tr>
<td>2002</td>
<td>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>
</tr>
<tr>
<td>2005-6</td>
<td>17-18 years old</td>
<td>Susan isolated herself with diabetes. People leave about her diabetes. She avoided talking about it with parents and friends. She felt isolated and alone. Eating disorder deteriorated, not yet addressed by HCPs. Lowest BMI: 16. SDC 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. 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. HbA1c from 117 to 86.</td>
</tr>
<tr>
<td>August 2009-March 2010</td>
<td>22 years old</td>
<td>Susan had nine months of non-attendance. Susan upset 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. HbA1c: 92.</td>
</tr>
<tr>
<td>March-Oct 2011</td>
<td>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 10 years. HbA1c: 81 HbA1c: 68.</td>
</tr>
<tr>
<td>December 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. HbA1c: 84.</td>
</tr>
<tr>
<td>October 2012</td>
<td>25 years old</td>
<td>Interview conducted by external interviewers HbA1c: 53.</td>
</tr>
</tbody>
</table>

In usual care
Susan found that the focus was on numbers. Susan experienced her situation deadlocked with diabetes. Since adolescence Susan had a pattern of eating disorder, poor glycaemic control and psychosocial distress. Despite 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. 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 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 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 benefited 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.

Contact details
Anette W. Christiansen, Lecturer
telephone: +45 7228 2851,
E-mail: anch@phmetropol.dk
Anne Prip, Lecturer
telephone: +45 7248 7405,
E-mail: anpr@phmetropol.dk