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RESEARCH ARTICLE

Educational and Psychological Aspects

Improved self-management of type 1 diabetes in young women: Experiences of Guided Self-Determination-Young: A qualitative interview study

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Abstract

Aims: Young women with type 1 diabetes (T1D) have higher risks of diabetes complications and report higher diabetes distress and lower quality of life than men with T1D. Their experiences of self-management and need for support have received little attention, and targeted interventions are lacking. The aim of this qualitative interview study was to explore the experiences of young women with T1D after participating in an intervention with the person-centred reflection and problem-solving model Guided Self-Determination-Young (GSD-Y), with a focus on self-management and support in daily diabetes care.

Methods: A qualitative interview study was performed in a paediatric and an adult diabetes outpatient clinic in Sweden. After participating in an intervention with GSD-Y, 12 women (15–20 years) with T1D were selected and interviewed individually. The interviews were analysed using inductive qualitative content analysis.

Results: The analysis revealed an overarching theme: 'A person-centred approach facilitated deeper reflection on both an individual and a relational level', and two main categories: 'The process initiated within the individual', and 'The process initiated together with the health care provider'. The women experienced increased knowledge of, and increased ability to manage diabetes. They also experienced a new type of relationship with the health care provider, including exchange of in-depth information beyond glucose levels, which appeared to increase their ability to receive support.

Conclusions: The GSD-Y model provided tools to explore and clarify the individual needs of young women with T1D, which supported diabetes self-management. Person-centred care was enabled when the women became engaged as active partners in diabetes health care.

KEYWORDS

adolescent, person-centred care, type 1 diabetes, women, young adult

1 | INTRODUCTION

Type 1 diabetes (T1D) is one of the most common chronic medical conditions among young people.[1] Self-management of diabetes is central to successful treatment and includes a series of daily decisions and actions to maintain satisfactory glucose levels and to minimise risks of diabetes complications. Many factors influence diabetes self-management, such as knowledge, experience, motivation, age and developmental stage and access to individualised support and care.[2] In adolescence and young adulthood, self-management can be particularly challenging, mainly due to intense biopsychosocial development and conflicting priorities.[3,4] High glycosylated haemoglobin (HbA_{1c}) during this period leads to increased risks of future diabetes complications, even in the case of improved glucose levels in adulthood.[5] Young women with T1D reach recommended glucose targets to a lower extent compared to men with T1D and have higher relative risks of vascular complications and premature mortality.[6–8] In addition, women with T1D report higher diabetes distress and lower quality of life than men.[9,10] Assessment and support of diabetes self-management is important as a well-functioning daily diabetes care is a prerequisite for optimal diabetes management.[11] There is limited research on young women with T1D and their experiences of diabetes self-management and support; however, previous studies have demonstrated that women appear to struggle more with integrating diabetes management into daily life and receive less support from their families compared to men.[2,12] In order to gradually take over responsibility for diabetes self-management, the young person with T1D needs to acquire both knowledge about T1D and skills while receiving adequate support from both legal guardians and health care providers (HCPs).[3,13] International guidelines recommend a person-centred approach to diabetes management and education of young people with T1D.[14]

Guided Self-Determination (GSD) is a theory-based person-centred reflection and problem-solving model and intends to guide the patient to become self-determined and to develop skills to manage difficulties in daily diabetes self-management.[15] The GSD model is flexible and can be provided individually or in groups and has been adapted to adolescents, GSD-Young (GSD-Y).[16] Previous studies with GSD and GSD-Y have suggested that an individual intervention with the model could be beneficial for young women with T1D.[16,17] Based on this, the GSD-Y was recently evaluated in a randomized controlled trial in young women with T1D, 15–20 years of age.[18] In this intervention, the GSD-Y model included the following components: (1) Seven individual communication and reflection sessions over 6–8 months together with an HCP educated in the model. (2) Specific GSD-Y worksheets prepared by the participant before each GSD-Y session and used during the sessions to stimulate reflection and problem-solving (not part of data collection) (Table 1). (3) The use of different communication methods (mirroring, active listening and value-clarifying responses) during the sessions to support communication and increase reflection.[15] Further details on the model are found in previous publications.[18,19]

What's new?

- Young women with type 1 diabetes (T1D) constitute a vulnerable group within diabetes care, but little is known about their experiences and need for support, and targeted interventions are needed.
- The person-centred model Guided Self-Determination-Young (GSD-Y) provided tools to explore and clarify the individual needs of young women with T1D.
- In young women with T1D, the GSD-Y model improved the ability to manage diabetes.

The aim of this qualitative interview study was to explore experiences of young women with T1D after participating in an intervention with GSD-Y, with focus on self-management and support in daily diabetes care.

2 | METHODS

2.1 | Research design and setting

This was a qualitative interview study evaluating the experiences of young women with T1D, 15–20 years, after participating in an intervention with the GSD-Y model.[18]

The Consolidated Criteria for Reporting Qualitative research (COREQ) checklist was used.[20] The study was conducted at the Unit for Youth at Sachsska Children and Youth Hospital, Södersjukhuset (15–20 years) and at the outpatient diabetes clinic at Ersta Hospital (18–20 years) in Stockholm, Sweden.

2.2 | Study sample

Purposeful sampling with a maximum variation strategy was used to identify information-rich cases that differed as much as possible to ensure the collection of relevant and in-depth data to answer the research question.[21,22]

TABLE 1 Overview of the content of the GSD-Y worksheets.

Session 1	**Your life with diabetes from the beginning to now**
	Written invitation to work together in a new way
	Two ways of looking at HbA_{1c}
	Agreement on things to work on
Session 2	**Your life with diabetes from the beginning to now**
	Important events and periods in your life
	What do you find difficult at present living with your diabetes?
	Your plans for changing your way of life
Session 3	**Values and opportunities**
	Unfinished sentences: needs, values, experiences and opportunities
Session 4	**Diabetes in your life**
	A picture or expression describing your life with diabetes
	Room for diabetes in your life
	Shared responsibility between adolescent and parent for diabetes in daily life
	Common name for difficulty in your life with diabetes
	Agreement on things to work on until next visit
Session 5	**Problem identification and problem solving**
	Current problem solving
	Dynamic problem solving
	Agreement on things to work on until next visit
Session 6	**Different ways of looking at numbers**
	Blood glucose tests and your reasons for checking
	Actual blood glucose numbers and wishes
	Your plan for blood glucose regulation in the short and long run
	Common name for a difficulty in your life with diabetes
	Agreement on things to work on until next visit
Session 7	**Problem identification and problem solving**
	Current problem solving
	Dynamic problem solving
	Solved problems and subjects to continue working on

Abbreviations: GSD-Y, Guided Self-Determination-Young; HbA_{1c}, glycosylated haemoglobin.

This strategy is time-efficient and aims at identifying and asking individuals who are particularly knowledgeable in, or have experience of, the phenomenon of interest to achieve trustworthiness.[23] The availability and willingness to participate, as well as the ability to communicate experiences were also considered.[23] Details on inclusion criteria in the preceding GSD-Y intervention are found in the study protocol.[18] After completing the GSD-Y sessions and based on a recommended sample size of 15 ± 10 interviews,[24] 10 young women were selected and asked by telephone to participate. After 10 interviews, we were not certain of having achieved data sufficiency.[25,26] After discussion in the research group, we decided to interview two additional young women after which we agreed that the collected data was sufficient, and that no new information was added.[26] Thus, 12 young women were interviewed, representing around 50% of participants in the GSD-Y intervention ($n = 25$). None of the young women declined when asked to participate.

2.3 | Data collection

Semi-structured interviews were conducted individually, 0–2 years after the GSD-Y intervention and were performed either face-to-face or by telephone/video calls and recorded to be transcribed verbatim into word files. These files were not reviewed by the participants. The interviews lasted for 25–80 min and were based on an interview guide. The questions covered different areas: experiences of the conversations and use of the worksheets in the GSD-Y intervention, changes in diabetes self-management and knowledge of diabetes, the impact on physical and mental health, as well as perceived support from the health care staff. The interview guide is added as a Supplementary File.

Nine interviews were performed by one or two specialist nurses in diabetes care (JBN and ML) and three by a senior consultant in paediatric diabetes care (JH), with no prior relation to the person they interviewed. The research team included only women.

2.4 | Qualitative analysis

Conventional inductive qualitative content analysis was used.[22] All interviews were performed before the content analysis. Initially, the analyses were performed by JH and ALB separately (steps 1 and 2).

The analysis included the following steps:

1. The transcribed interviews were read repeatedly to gain an overall view of the data.
2. Meaning units were identified in the text, condensed and labelled with codes close to the text.
3. The codes were discussed and compared, looking for differences and similarities, verifying that they matched the meaning units. Codes were then sorted and divided

TABLE 2 Examples from the content analysis.

Meaningful unit	Condensed unit	Code	Subcategory	Category
I would say that I am much better at taking insulin and so, than I was, it has improved a lot. I see it as part of my life now with diabetes	I am much better at taking insulin than I was. I see diabetes as part of my life now	Diabetes as part of life	Process of change to accept and integrate diabetes in daily life	The process initiated within the individual
It was probably that it was much more how I felt, not just what HbA_{1c} I had	It was more how I felt, not just HbA_{1c}	Focus on feelings, not just values	Changed type of visits: focus, structure and content	The process initiated together with the health care provider

Abbreviation: HbA_{1c}, glycosylated haemoglobin.

into subcategories. Based on the subcategories, two main categories emerged.
4. The codes and the classification of subcategories and main categories were carefully discussed in the research group, resolving differences and arriving at common terms. Examples from the analysis are found in Table 2.

The categories were assessed based on internal homogeneity (all data belonging to the same category have clear similarities) and external heterogeneity (the differences between the categories were clear).[27] The analysis was based on a manifest interpretation of the text, describing the explicit content of the text without interpretation.[23] At the end of the analysis, a latent interpretation of the content was made, and an overarching theme emerged.

2.5 | Ethics approval

The Ethical Review Board in Stockholm approved the study (2014/1942-31/2, 2016/155-32), which was carried out in accordance with the Declaration of Helsinki. Participants received both verbal and written information about the study and written informed consent was obtained.

3 | RESULTS

At inclusion in the preceding GSD-Y intervention, the mean age of the women who were interviewed was 18 years (SD 1.2) and the mean duration of diabetes was 11.2 years (SD 4.4). Furthermore, 75% lived with their parents, 50% studied and 50% worked. For further details on each one of the participants, see Table S1.

The qualitative content analysis revealed an overarching theme: A person-centred approach facilitated deeper reflection on both an individual and a relational level, and two main categories: (1) The process initiated within the individual, and (2) The process initiated together with the health care provider. The overarching theme, categories and subcategories are visualized in Figure 1. Overall, the importance of increased knowledge, self-reflection, and self-awareness in relation to the individual's diabetes was highlighted, as well as the importance of a different approach in the meeting between the young woman with T1D and the HCP. On an individual level, the perception of diabetes as an integrated part of life became stronger throughout the sessions, which improved the ability to manage diabetes. On a relational level, the mutual exchange of in-depth information about the individual, and not only about the disease and glucose levels, appeared to increase the ability to receive support. When the participants became engaged as active partners in diabetes health care, person-centred care was enabled.

3.1 | The process initiated within the individual

3.1.1 | Increased knowledge and insight

Initially, some young women were sceptical when entering the study and found it difficult to talk about themselves. However, this notion was gradually replaced by curiosity during the subsequent GSD-Y sessions. Several of the participants highlighted difficulties with having people around them not understanding what it is like to live with T1D. Several also described that they had gained insight into previous behaviours, such as ignoring the fact that they had diabetes.

> ...that's why it felt hard when you tried to pretend it (diabetes) didn't exist before...
> (W1, aged 17, 1 year since taking part in intervention)

Most of the young women described increased knowledge and insight, both of T1D and its consequences on their physical health, and of the way the disease influences

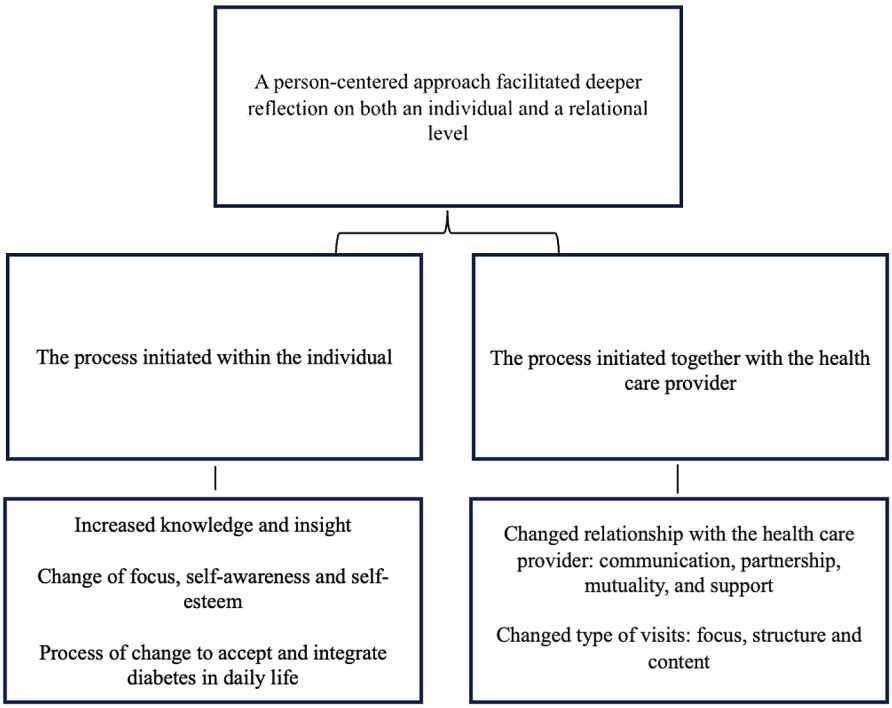

FIGURE 1 Description of overall theme, main categories and subcategories.

life, priorities, feelings and behaviour. Furthermore, they expressed having learned more about themselves and their own diabetes during the intervention, which was perceived as positive.

> I kind of got to know my diabetes in a better way after than before...
> (W11, aged 16, 1.5 years since taking part in intervention)

3.1.2 | Change of focus, self-awareness and self-esteem

The young women perceived a change of focus, with new insights into the possibility of making a change and being motivated to change. They also described how the sessions enabled reflection and made them identify and highlight areas to work with, which in turn led to change.

> I see a big change in myself like in the way I think and feel about my diabetes and just being able to put things into words that have to do with my diabetes that maybe you should have known before...
>
> (W3, aged 19, 1 month since taking part in intervention)

Some young women experienced fewer feelings of loneliness after the intervention and felt inspired to help others with T1D. Furthermore, some perceived a change resulting in increased individual responsibility, better glucose levels and general health.

In addition to the change of focus, increased knowledge and reflection, some women described how their self-awareness improved during the GSD-Y sessions, which promoted personal development. The young women experienced improved self-esteem, feeling proud of themselves, with a more positive view of themselves and fewer feelings of shame.

> I don't think I look down on myself as much connected to the diabetes.
> (W2, aged 19, 2 years since taking part in intervention)

3.1.3 | Process of change to accept and integrate diabetes in daily life

The young women experienced new ways of thinking and a changed approach regarding their diabetes, which included a wish to take control of the disease, increased openness and honesty towards others and respect for their own choices.

> What good is it if I sit here and lie or pretend that this is not a problem, I kind of have to be completely honest if there is to be any result.
> (W3, aged 19, 1 month since taking part in intervention)

Some women described that they had started to prioritize their diabetes to a higher degree, using new tools in managing diabetes. They found it easier to express their feelings after GSD-Y sessions, and one noticed fewer conflicts at home, with increased understanding from the family. However, the adaptation to better self-care was perceived as difficult, and the process of change took time and continued after the end of the intervention.

Several of the young women described diabetes as being more integrated into their lives and most experienced a higher acceptance of diabetes. Before the GSD-Y intervention, one participant also described that she had denied having diabetes.

> Before....it was really like completely denying that I even had diabetes and really pretending that I didn't have it. But now...it's a part of life. Or my life anyway...I am prouder of it...it is my illness, and my life.
> (W10, aged 16, 2 years since taking part in intervention)

One participant experienced coming more to peace with her diabetes after the work she had done during the GSD-Y sessions:

> ...you should describe your diabetes with some word....and I described my diabetes as my enemy...after that we worked a lot on just that and now in retrospect, I can say that I look at diabetes in a completely different way...
> (W2, aged 19, 2 years since taking part in intervention)

3.2 | The process initiated together with the health care provider

3.2.1 | Changed relationship with the HCP: communication, partnership, mutuality and support

After participation, most of the participants described a new type of relationship with the HCP. One young woman also pointed out she had gained increased acceptance from the rest of the diabetes team. A good relationship with the HCP appeared to facilitate the conversation, and some young women expressed they now understood the importance of who you have around you, and that the HCP's engagement mattered.

> You benefit from actually knowing the person you are sitting and talking to.
> (W5, aged 19, 1 year since taking part in intervention)

After the GSD-y sessions, some of the women felt less lonely and were happy they now had someone to talk to. This made it easier to motivate them to come to the hospital.

> ...and now that I felt that they understood me, and I understood myself and we started talking about how we can help me then it was somehow even easier to come.
> (W6, aged 17, 2 years since taking part in intervention)

The young women described new ways of communicating with the HCP that enabled sharing what was hard to manage. They experienced increased understanding, flexibility and support from the HCP, as well as being more open with their diabetes, which helped them to identify and work with diabetes-related problem areas.

> ...when I worked on these work sheets then I became much more open about diabetes and talked more about it and accepted it a little more...that helped...
> (W1, aged 17, 1 year since taking part in intervention)

3.2.2 | Changed type of visits: focus, structure and content

In particular, the participants appreciated having person-centred conversations, compared to focusing primarily on glucose levels. The focus of the conversations was on their own feelings, desires, thoughts and on problem-solving.

> It was probably that it was much more how I felt, not just what HbA_{1c} I had.
> (W5, aged 19, 1 year since taking part in intervention)

Talking alone with the HCP was appreciated, and some of the participants described having a parent in the room as a barrier. It was considered positive to be able to talk about different problems, feelings and mental well-being in a non-judgmental way. The communication also improved by participating actively in the meeting and being able to decide topics of conversation. The focus on opportunities instead of failures was perceived to enable change.

> ...but now there were more possibilities and then it was ok...that you don't look at what you've done wrong...that you don't stop there, that you move forward...
>
> (W1, aged 17, 1 year since taking part in intervention)

Some participants were not used to leading the conversation themselves, and some found it hard to work with one problem at a time. Frequent meetings made a difference.

> ...I think it was this thing that you met so many times in a row and really felt like you got hold of it once and for all...
>
> (W5, aged 19, 1 year since taking part in intervention)

The participants described an ongoing process of increased reflection both during and in between the different sessions. However, some pointed out that the increased reflection did not necessarily lead to change. The GSD-Y model and the working sheets were generally appreciated, even though the sessions were described as both tough and time consuming, requiring ambition and discipline. It was also easy to forget to bring the work sheets to the sessions, and sometimes the work sheets were found difficult to fill in. Furthermore, participants described how some questions made them irritated and upset. One participant described the sessions as a being on a roller coaster (W9, aged 19, 1 year since taking part in intervention).

4 | DISCUSSION

In this qualitative interview study, experiences from an intervention with the GSD-Y model in young women with T1D were explored. As far as we know, this is the first time a person-centred education is evaluated only in young women with T1D, specifically addressing their experiences. The structure of the GSD-Y model and the communication models used appeared to facilitate deeper reflection on both an individual and a relational level and brought up topics for communication that otherwise would not have been discussed. This, in turn, had a positive impact on both diabetes self-management and the ability to receive support. In addition, the GSD-Y appeared to meet some of the unique needs young people have in health care by providing flexible and frequent meetings with a clear content and structure.

There are limited previous reports on experiences of diabetes self-management in young women with T1D, but one study has demonstrated that the ability to be active in diabetes self-management and how you act on and perceive your diabetes may affect HbA_{1c} more in women with T1D than in men.[28] However, there are conflicting results on sex differences in diabetes self-management in youth.[11]

The young women in the present study demonstrated a capacity to identify what they needed to make changes in diabetes self-care, to prioritize what they were willing to change, and to motivate their choices. In consistency with previous studies, the process of change promoted the integration of diabetes in their lives.[16,17] Along with being motivated to make a change, most of the young women experienced increased knowledge and understanding of their own diabetes in terms of both emotions and physical health, which may impact and improve diabetes self-management. In line with findings in an earlier GSD-Y intervention, participants also described that the newly gained knowledge increased their ability to understand and help others.[29] Furthermore, the GSD-Y model appeared to promote personal development, and several of the young women described a change in autonomy and a transition from feelings of shame to being proud of oneself, which may enable increased responsibility for diabetes self-management.[13] In consistency with previous GSD and GSD-Y studies, several of the young women expressed fewer feelings of loneliness.[29,30] It is unclear whether young women with T1D experience more loneliness than other young women. However, studies support that loneliness is more common in young people with physical chronic conditions.[31]

Adequate support from health care is often crucial for a young person to manage diabetes.[14] However, receptivity to receive support may depend on both individual factors and the relationship with the HCP. Consistent with our findings, experiences from earlier GSD interventions demonstrate not only changes within the individual but also in several areas outside the individual sphere, such as a changed relation with the HCP and changed attitudes towards the hospital, families, and friends[15,30]—changes that alone can be useful in both daily life with T1D and enable increased support from health care. It is well known that the relationship between a young person and the HCP is important to create emotional safety,

openness, and trust[32,33] and the GSD-Y sessions appeared to provide a safe zone for reflection and in-depth conversations between the young women and the HCP. One can speculate whether the increased frequency of visits, and not the GSD-Y model itself, affected results in the present study. However, the participants clearly expressed they especially appreciated the person-centred conversations beyond glucose levels and glucose targets, with focus on opportunities and their own thoughts, feelings and experiences. These findings are also in line with a recent integrated review which clearly outlines the beneficial effects of the person-centred approach in GSD models.[30]

The GSD-Y highlighted the person's narrative and experiences, thus promoting one of the cornerstones of person-centred care.[34] A starting point for person-centred care in young people may be the opportunity to become an active partner in health care to form a partnership with the HCP.[34] The young women in the present study appreciated becoming part of communication and decisions, and in line with earlier GSD studies, shared decision-making was enabled in the exchange of person-specific knowledge from the participant and disease-specific knowledge supplied by the HCP.[15] Shared decision-making and meaningful support may both improve diabetes self-management.[2]

As in a previous study, some participants perceived the GSD-Y model to be both challenging and time consuming.[29] However, most experienced having benefitted from the GSD-Y, both by increased knowledge and focus on their own diabetes, as well as through an exchange of knowledge with the HCP, thus enabling person-centred care.[34]

Although recommended, psychoeducational interventions in young people with T1D rarely demonstrate significant effects on health-related outcomes.[14] In addition, a recent systematic review investigated self-determination theory interventions compared to standard care and demonstrated no effect on either primary or secondary outcomes.[35] However, this review identified the worksheets used in guided self-determination as potentially beneficial tools, compared to other self-determination methods, to help incorporate self-determination in clinical practice.[35] Further, the GSD-Y model has been shown to promote conversations about new topics.[29] Another advantage of the GSD-Y model is that it can be provided by HCPs (physicians, nurses or nutritionists) in daily clinical practice.

4.1 | Strengths and limitations

The present study addresses a patient group that is rarely focused on in research, both in terms of sex and age, including both adolescents and young adults. The multicentre design with participants from both a paediatric and an adult diabetes outpatient clinic contributed to a varied study population. Qualitative methods may enable deeper understanding of results from interventions or other types of studies and create new questions and ideas for future research. Qualitative content analysis is a well-recognized method with high sensitivity to the content[22] and contributed to a more complete evaluation of the preceding GSD-Y intervention. We aimed to describe all steps in the qualitative content analysis as correctly as possible to achieve trustworthiness and documented all the decision-making processes, the data collection and analysis.[21] There was extensive experience of qualitative content analysis in the research group. To promote confirmability, the initial analysis was done separately by two researchers before they compared and discussed with each other and with the research group. Quotations were used to strengthen the findings.[23] In literature, it is unclear how many participants are recommended to achieve sufficiency and methodological saturation.[25,26] A recent systematic review recommended 9–17 interviews, with an average of 12 interviews, to reach data saturation.[25] In the present study, the researchers experienced sufficient data collection after 12 interviews.

One limitation in the present study was the transferability of the results since the study was conducted only with participants already selected based on inclusion criteria in the preceding intervention and living in a metropolitan region in Sweden. Further, data on ethnicity was not collected either in the preceding intervention or in the present study. The use of purposeful sampling contributed to a risk of bias in the selection of participants to interview, which may have led to difficulties in judging trustworthiness.[21] The researchers' prior knowledge of both T1D and the GSD-Y may have influenced both the interviewing and interpretations, which may have limited the accuracy of the analyses, dependability and credibility.[23] The participants' awareness of the researchers' involvement in the intervention could have limited them from speaking freely about the GSD-Y, including potential negative experiences. Different time intervals between the intervention and the interviews may also have limited trustworthiness; however, we experienced consistent results regardless of time interval.

The GSD-Y work sheets were time-consuming and, for use in clinical practice, a compressed and updated version should preferably be developed and re-evaluated.

In summary, we find the GSD-Y model to be a promising tool for use in clinical practice and suited for meeting the unique needs of young women with T1D in adolescent and young adult care by increasing possibilities of both integration of diabetes in life and of improved diabetes self-management and support from health care.[2,12] The

present study only evaluated experiences in young women with T1D, thus limiting conclusions on potential effects in other patient groups. However, the GSD and GSD-Y models have previously been evaluated in clinical interventions and qualitative research in both young and adult people of both sexes, demonstrating impact on health-related outcomes and being well accepted by both participants and HCPs, thus with a potential of being useful in clinical practice in other patient groups.[30]

5 | CONCLUSIONS

Person-centred education methods are recommended in the care of young people with T1D. The GSD-Y model provided tools to explore and clarify the individual needs of young women with T1D, supporting their ability to manage T1D. The GSD-Y model appeared to meet several health care needs of young women with T1D by providing flexible and frequent meetings with a clear structure, and with communication methods enabling a mutual exchange of both person- and disease-specific knowledge, which is the basis for person-centred care. In summary, the GSD-Y model can be valuable in the care of young women with T1D.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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