

# What it is like being a sibling of a child newly diagnosed with type 1 diabetes: an interview study

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## Introduction

Type 1 diabetes (henceforth referred to as diabetes) is recognised as a chronic illness affecting all family members.<sup>1–4</sup> It is considered to have a disturbing impact on previously existing family patterns, resulting in new ones having to be constructed.<sup>5</sup> Consequently, it is recommended that diabetes educational programmes are personalised to the needs of the affected child and her or his family, not forgetting the healthy sibling(s), as they may feel neglected because of the increased attention paid to the child due to the illness<sup>6</sup> – attention that may cause feelings of jealousy toward the affected child, as well as feelings of anger and competition, increasing the sibling rivalry.<sup>5,7,8</sup> The illness has also been demonstrated to lead to siblings worrying about their own health and the risk of developing diabetes themselves.<sup>5,8</sup> Furthermore, siblings have been known to experience a need to take

## Summary

Although previous studies have stressed that having a brother or sister with a chronic condition may affect the healthy sibling, few have specifically focused on healthy siblings of children with type 1 diabetes.

Hence, this study aimed to illuminate what it is like to be a brother or sister of a child newly diagnosed with type 1 diabetes.

Individual interviews were conducted with seven siblings aged 10–17 years (median=12) from six different families. Each interview was analysed using content analysis.

Three different categories emerged – *Living differently*, *Being concerned* and *Participating in caring for the affected child* – indicating that, for the healthy sibling, the illness entails a transformed everyday life including worry about the affected child and the need to help in the home.

In conclusion, the paediatric health care service may need to develop new strategies to meet the siblings' desired level of knowledge in educational team sessions related to diabetes. As the sibling relationship is probably the longest one that an affected child will experience in her/his lifetime, it is worth investing in it to promote this long-term support resource.

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## Key words

diabetes mellitus; type 1; interview; nursing; siblings; qualitative research

on a greater responsibility, due to the illness, in caring for the affected child.<sup>5,7,8</sup> Thus, having a sister or brother with diabetes may lead to psychological, physical and developmental consequences for the healthy sibling.<sup>7–10</sup> Previous studies have described siblings' experiences including data on the affected child,<sup>11</sup> their parents,<sup>3,9,12</sup> or both,<sup>2,13–18</sup> and relatively few have illuminated experiences of being a brother or sister of a child with diabetes described solely by the healthy siblings themselves.<sup>5,7,8,19</sup> Hence, this study aimed at illuminating what it is like being a sibling of a child newly diagnosed with diabetes.

## Materials and methods

### Participants

The sample was taken from a larger sample of a consecutive series of 12 families (n=42 family members),

from one of the national paediatric diabetes centres at a children's university hospital in Sweden, in 2003.<sup>2</sup> Inclusion criteria were: sibling of a child newly diagnosed with diabetes, aged seven years or older, and able to speak and understand Swedish. The age limit was set at six years, as at that age children are considered to possess the necessary cognitive and language capabilities to be interviewed.<sup>20,21</sup> One sibling in two families declined to participate, while the remaining seven (five boys and two girls) from six different families were included. The siblings, who ranged in age from 10–17 years (median=12), came from one reconstituted family, one family with cohabiting parents and four families with married parents. All were older than the affected child, and in one of the families one parent had diabetes. The affected

children ranged in age from 8–13 years (median=9.5).

#### Data collection

A qualitative interview approach was selected, as interviews are considered an especially important means of obtaining information from children.<sup>22,23</sup> Within two weeks of diagnosis the responsible paediatric diabetes nurse gave the families age-specific written information about the study and a consent form allowing the first author (AW) to contact them. This time-lapse was chosen as previous research has suggested that children should be interviewed as soon as possible after their experience of a target event, because it yields the most accurate information.<sup>24</sup> Thus, the interviews were scheduled within two months of the affected child's discharge from the hospital.

To create a natural context, the interview was performed at the participants' convenience. This was normally in a secluded room in their home environment during evenings, weekends or holidays. All interviews were conducted privately by the first author (AW), as previous research has indicated that children may withhold information about unpleasant experiences because they do not want to elicit a negative response in front of other family members.<sup>25</sup> To allow the respondents' concerns to emerge, the interviews began by inviting the siblings to tell, in their own words, their experiences and thoughts at the time when the affected child became ill. This unstructured approach was decided upon, as previous research<sup>26,27</sup> has found it more likely to capture the child's unique perspective. Follow-up questions were only posed for the purpose of clarification and to prompt discussion. The interviews were recorded for transcription and lasted from 10–30 minutes.

#### Data analysis

Each interview was transcribed verbatim and analysed using content analysis influenced by Burnard.<sup>28</sup> To enhance dependability as well as to become immersed in the data and gain a sense of the overall text, both authors independently read through the transcriptions. Both authors have experience of diabetes from several years as Registered Sick Children's Nurses at two different children's hospitals in Sweden. Throughout the reading, notes were made on general themes, after which the interviews were read again, headings describing the content were identified (open coding) and 'dross' excluded. Each author's notes were compared and the number of headings reduced and grouped into categories, after which the transcripts were re-read alongside the list of categories. Sentences and paragraphs where the research question, 'What is it like being a sibling of a child newly diagnosed with type 1 diabetes?', was mentioned or inferred were highlighted. Subsequently, each section was cut out and sorted under the appropriate heading, and, after discussion, under a suitable category.

#### Context

At diagnosis, the inpatient stay involves several educational team sessions where age-specific education is provided based on national, family-centred guidelines.<sup>29,30</sup> Accompanied by one parent, the affected child is hospitalised for approximately 14 days during which family members, including the healthy sibling and friends, can visit. As soon as the affected child's symptoms are under control, she/he is temporarily discharged to try out the diabetes management regimen at home with the rest of the family. After discharge the affected child and the family are managed on an outpatient basis.

#### Ethics

Using written age-appropriate information about the study, in accordance with the World Medical Association's Declaration of Helsinki,<sup>31</sup> the sibling's willingness to participate was obtained by the parents and mediated to the first author (AW) by telephone. This enabled the siblings to make a decision together with their parents who know them best and can therefore foresee the consequences of participation. Written informed consent from all parents was obtained at the time of the interview, and at the same time oral age-specific information was given to the sibling so that the first author (AW) could be certain about her/his willingness to participate. Having been allowed time to reflect, siblings over the age of 12 years gave their written consent, whereas younger siblings gave verbal and written assent. After the interview, the interviewees and their parents were given information about whom to contact if the interview raised further questions or thoughts. The study was approved by the appropriate research ethics committee (LU 159-03).

#### Results

The analysis revealed three categories that illuminate what it is like being a sibling of a child newly diagnosed with type 1 diabetes: *Living differently*, *Being concerned* and *Participating in caring for the affected child*. The categories are reported below together with quotations from the interviews to support the confirmability of the findings.

##### *Living differently*

Being a sibling of a sister or brother newly diagnosed with diabetes entailed a transformed everyday life, which implied physiological as well as structured and psychological aspects. During the first phase after

diagnosis, the siblings found the affected child marked by the illness, which made it clear that she/he had gone through a physiological change. They found it odd to see the affected child monitoring her/his glucose levels and taking insulin. As one sibling said: '*...She has diabetes and takes injections and blood glucose tests and things like that. It's not like before...*' (I.P., 3). Gradually, however, all of this became a normal feature of the siblings' everyday lives.

Living with an affected child also entailed a more structured life. Instead of eating when hungry, siblings had to adjust their food intake to the needs of the affected child. This resulted in having to follow a schedule for when to eat and adjusting to the needs of the affected child. As one sibling expressed: '*...We are more at one with her, her times and what she needs...*' (I.P., 4). Thus, the siblings experienced their life as structured according to the regimen, especially when it came to food and eating.

Since becoming ill, the affected child was experienced as more easily irritated and to have mood swings, so the siblings felt that they had to be more patient. As one sibling said: '*...He has changed rather a lot. He has a whole lot of mood swings so you can get very upset. He just screams ... it's annoying. At the same time he has ... become a bit different ... older in some way. He takes responsibility and so on...*' (I.P., 2). The psychological change was not only seen in the affected children but also in their parents. Although it was difficult to put one's finger on it, one male sibling described his father as having become friendlier. Moreover, the family, especially the parents, were perceived as giving the affected child more attention than previously. The siblings considered this understandable, as they felt sorry for the

affected child who was compelled to manage the illness.

#### *Being concerned*

Learning about the affected child being diagnosed with diabetes was described as difficult. The siblings felt that they knew little about the illness and feared that it would ruin their sister's or brother's life. The fact that the affected child had to regularly puncture her/his fingertips as well as inject insulin reminded them of their concern, as they worried that the syringe might hurt. Needle pricks sometimes made the affected child burst into tears or cry out. Another frightening piece of information was that, due to the illness, the affected child could experience an insulin reaction. As one sibling said: '*...When he doesn't want to take his insulin I say if you don't take the injection you will have an insulin reaction...*' (I.P., 5). However, the siblings considered that this was not a problem for their parents to deal with, as they felt that they had enough worries. Instead, they mentioned a recurrent need to ask the affected child if she/he felt well.

The siblings felt the need to verify that the affected child was okay and not experiencing any signs of hypoglycaemia, but feared that she/he would answer anything else but fine. Unfamiliarity with the management of the illness and thus the need for further information led to this fear. In addition to questions concerning the regimen, the siblings worried about the future health of the affected child and experienced a need to comfort her/him with hopes about a cure for diabetes. As one sibling said: '*...It might be difficult when they are small, but to repeatedly tell them that everything is going to be all right and that they are about to find a cure for diabetes, that it will be here shortly ... that's important...*' (I.P., 7). Their concerns resulted in a wish to be

invited more often to the hospital educational team sessions, and for the hospital staff to help the sibling to take a brighter view of the future and feel confident. Since the hospital educational team sessions were normally scheduled on weekdays and during school hours, siblings visiting the affected child after school or on weekends experienced an unfulfilled educational need in relation to the illness and its management.

#### *Participating in caring for the affected child*

Being a sibling of an affected child who was hospitalised meant living separated as a family. While one parent stayed overnight at the hospital, the other managed the household between hospital visits. Although this was considered understandable, as it implied company for the affected child instead of her/him being all alone, it was difficult as it meant that the siblings had to assume more responsibility at home. As one sibling said: '*...I had to do more chores, things my mother normally does...*' (I.P., 6). Thus, it was described as positive when the family was reunited after discharge. As one sibling remarked: '*...It felt good when he [the affected child] came home...*' (I.P., 1). Discharge did not imply less responsibility but being able to share it with the entire family, which relieved pressure on the sibling. The sibling quoted above continued: '*...Now I don't have to help as much as before...*' (I.P., 6).

Helping out at home did not only consist of housekeeping but also involved assisting with blood glucose testing and motivating the affected child when they did not want to follow the diabetes management regimen. Thus the siblings assisted their sister/brother by monitoring her/his glucose level whenever the affected child needed a break from the testing. The fact that

the whole family participated in caring for the affected child improved their unity and made the siblings feel that all family members had become closer.

### Discussion

Perhaps the most interesting finding in this study is that siblings need information about the affected child's illness and the opportunity to participate in educational sessions with the paediatric health care service in order to understand the impact of the illness and to assist the affected child with the diabetes management. Additionally, they feel a need for positive support from the health care service, in order to instil a feeling of hope in the affected child when visualising her/his future. Thus, despite their close involvement in its management, siblings have a limited understanding of the newly-diagnosed illness.

The finding that siblings wished to know more about diabetes due to their involvement in their sister's or brother's diabetes management was supported by Adams.<sup>19</sup> The mean duration of diabetes among the affected children in Adams' study was 7.3 years, and the siblings did not recall any individual discussions with a professional, e.g. doctor, nurse or teacher. When interviewing adult siblings aged 22–45 years who were 1–19 years of age at the time of diagnosis, Smith<sup>5</sup> also found a lack of professional input pertaining to the sibling's knowledge of diabetes. Instead, they learned by watching, receiving instructions from the affected child or through reading. The results of our study, performed 12 years after the publication of Adams' study<sup>19</sup> and five years after that of Smith,<sup>5</sup> indicate that siblings still desire more knowledge when their sister or brother is stricken with diabetes.

Previous research has revealed that siblings are highly capable of

and competent in mastering their external world due to their empirical knowledge of the illness.<sup>8</sup> Simultaneously, they experience psychological distress that manifests itself internally irrespective of gender, ordinal position and family size. The distress is, however, not shared. According to the participants in our study, the most distressing aspect of being a sibling of a child newly diagnosed with diabetes is the risk that she/he might experience an insulin reaction. However, as in the study by Hollidge,<sup>8</sup> this is not discussed with their parents, as they do not want to burden them with any additional worries. Similar findings were also presented in Smith's study<sup>5</sup> and mentioned in the study by Adams.<sup>19</sup>

To moderate their fear, the siblings in our study developed their own strategy, implying frequent questions about the affected child's wellbeing in order to identify signs of hypoglycaemia. In Herman's study,<sup>7</sup> siblings followed the affected child everywhere or watched her/him all the time to make sure that all was well. According to Smith,<sup>5</sup> this vigilance and protectiveness begins in childhood, and continues and intensifies as the affected child enters adulthood. Hence, it would be interesting to conduct follow-up interviews with the siblings to study their educational needs over time when having a sister or brother diagnosed with diabetes. As the sibling relationship is probably the longest one that an affected child will experience in her/his lifetime, it is worth investing in the promotion of this long-term support resource.

### Methodological considerations

To build trust and enhance the credibility of the findings, the first author (AW) who performed the interviews spent a couple of hours with the family before interviewing the sibling. Until recently, children

have been considered to lack the verbal skills, conceptual abilities, recall and overall narrative competence to convey their experiences, which is why the bulk of knowledge available is based on the perspectives of parents and/or paediatric health care professionals.<sup>25,32</sup> It may also explain why previous research illuminating experiences of being a sibling of a child with type 1 diabetes is sparse. Hence, our study can constitute a valuable contribution, although the interview duration of 10–30 minutes (mean 15 minutes) may be considered short. Previous research has demonstrated that older children have increased ability to communicate their experiences in greater detail<sup>25</sup> and that their recollection improves with age.<sup>24</sup> This was also evident here, as interviews with older siblings were longer (range=20–30 minutes) than those with younger siblings (range=10–20 minutes).

Since the interviews were gathered, in 2003, the hospital-based care has been consistent. However, a randomised control trial comparing hospital-based care and home-based care when a child is newly diagnosed with diabetes was performed during March 2008 to September 2011.<sup>33</sup> Affected children, aged 3–16 years of age, were randomised to either hospital-based care as described previously (see the heading 'Context') or hospital-based home care. Thus, the findings of this study may lead to future alternative ways of providing care to affected children and their families.

### Clinical implications

The paediatric health care service may need to develop new strategies to meet the siblings' desired level of knowledge in educational team sessions related to diabetes. Encouraging siblings to prioritise team sessions over school attendance if only for a short period,

or scheduling the sessions after school hours, may be beneficial. Arranging a sibling session as a supplement to regular family sessions may also be helpful. Siblings meeting and sharing experiences, while the paediatric health care service provides lectures about diabetes and reports ongoing research, may be yet another good way of fulfilling their needs.

### Declaration of interests

There are no conflicts of interest declared.

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