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## Experiences and needs of children with siblings diagnosed with Type 1 diabetes: A mixed studies systematic review



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### ABSTRACT

**Problem:** The lives of family members for children with Type 1 diabetes mellitus (T1DM) after often shaped around the diagnosis as long-term/life-long care is needed. The combination of illness symptoms, treatment cost, and caregiving demands for T1DM negatively affects family functioning. While the experiences and needs of both parents and children suffering from T1DM are well documented, literature on healthy siblings of children with T1DM remains scarce.

**Purpose:** This systematic review aims to consolidate and examine the experiences and needs of siblings of children with T1DM.

**Eligibility criteria:** Qualitative and quantitative studies exploring the experiences and needs of children under 18 years old whose siblings are diagnosed with T1DM.

**Sample:** Six electronic databases (PubMed, CINAHL, PsycINFO, EMBASE, Scopus and ProQuest) were searched from inception till July 2021. Thirteen studies met the inclusion criteria and were subjected to narrative synthesis.

**Results:** Four themes were generated from the synthesis: (1) emotional responses to sibling's condition, (2) stepping out of comfort zone, (3) changes in family dynamics, and (4) takeaways and a way forward.

**Conclusions:** The impact of T1DM diagnosis on siblings of children with T1DM suggest a need for healthcare providers to provide them better emotional and informational support, and allow them more involvement in the care for their sibling with T1DM.

**Implications:** Findings from this review will be able to inform policymakers on the development of future support programmes for children with T1DM and their families and encourage clinicians to revise T1DM care plans to be more family-centered.

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### Background

With the advancement in medical treatments and technology, the morbidity and mortality rate of infectious diseases among children has declined but there is increased morbidity of chronic diseases, such as Type 1 diabetes mellitus (T1DM) among children (Maahs et al., 2010). Given the prolonged nature of T1DM, the quality of life of children and adolescents with T1DM is a crucial determinant in disease management and prognosis (Cherubini et al., 2014; Dinleyici & Dağlı, 2018). However, the diagnosis of a paediatric T1DM does not solely affect the child. Long-term or life-long care may be needed, and the lives of family members are often shaped around this diagnosis. The combination of illness symptoms, treatment cost, and caregiving demands for T1DM may negatively affect family functioning (Limbers & Skipper, 2014); therefore, it is necessary to understand the impact of a T1DM diagnosis on the whole

family. Currently, there is a sizeable amount literature and reviews examining the experiences and psychological outcomes of parent caregivers of children with T1DM (Hassounah et al., 2020; Kimbell et al., 2021; Simpson et al., 2021; Whittemore et al., 2012). However, literature consolidating the perceptions, needs, and outcomes of healthy siblings of children with T1DM remain scarce.

Siblings significantly influence one another's development as they play the role of social partners and model good behaviours. Interacting and engaging with one's sibling may positively impact the ability of children with T1DM to adjust and adapt (McHale et al., 2012). As the two siblings may be of similar age, the sibling may cultivate some form of independence while caring for the child with T1DM. Similarly, caring for a sibling with T1DM may enhance their perspective and social understanding of the disease (East, 2010). As T1DM is a chronic and life-threatening disease, it may result in caregiver burden for siblings in the long run. Furthermore, the fear of the effects of insulin therapy may cause siblings of children with T1DM to develop psychological problems (Driscoll et al., 2016). A previous study has shown that

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siblings who cared for children diagnosed with chronic diseases may be impacted psychologically. As parents are more preoccupied with the child with T1DM, their lack of attention to the other children contribute to the children feeling neglected and lonely (Dinleyici & Dağlı, 2018). Therefore, healthcare professionals must recognise that siblings may be caregivers, and establish support services for them (Namkung et al., 2017).

There has been extensive work to document the difficulties and first-hand experiences of both parents and children suffering from T1DM. However, it is also crucial to understand the needs and challenges faced by siblings. This will allow healthcare professionals to develop, tailor and implement family-centred support services to help siblings of children with T1DM to resolve and cope with the impact of caregiving. Additionally, siblings' perspectives are normally interpreted and recounted by their parents instead of obtaining a first-hand account of their experiences (Dinleyici & Dağlı, 2018). Thus, it is essential to consolidate and explore siblings' first-hand experiences to obtain an accurate overview of their experiences and needs.

Currently, there is a paucity of literature examining the experiences of siblings of children with T1DM. A narrative report by Dougherty (2015) recorded details of siblings' experiences without conducting the thorough process of a systematic review. Although systematic reviews by Gan et al. (2017) and Yang et al. (2016) reported that a sick child's condition may affect other siblings psychologically, both reviews included children with various chronic illnesses including cancer, thus it is inaccurate to generalise these findings specifically to the siblings of children with T1DM. Another systematic review done by Begg (2016) documented the impact of T1DM on parents and the sick child. However, it focused on the experiences of both parents and the child with T1DM, and barely mentioned the impacts of the T1DM diagnosis on siblings. Begg (2016) also mentioned that more research is required to understand the experiences of siblings. To date, no systematic review has been done to document the experiences and needs of siblings of children with T1DM, and this forms the rationale of this review. Therefore, this systematic review aims to consolidate and examine the experiences and needs of siblings of children with T1DM to inform clinicians and relevant stakeholders on ways to better support children with T1DM and their families to achieve optimal quality of life and family dynamics.

## Methods

### Study design

A mixed studies systematic review using narrative synthesis was conducted. While qualitative studies are crucial for providing rich, in-depth subjective information on siblings' first-hand perspectives, quantitative studies provide objective measurable data and information (Almeida et al., 2017). Therefore, by consolidating evidence from qualitative and quantitative studies, a mixed studies systematic review will be able to provide an in-depth and holistic understanding of the healthy siblings' experiences and needs (Tariq & Woodman, 2013). The systematic review protocol was registered in PROSPERO and conducted in accordance to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). The PRISMA checklist is presented in Supplementary material 1.

### Search strategy

The database search approach was modelled after the steps recommended by (Lefebvre et al., 2019). An initial search in databases and journals was conducted to identify similar systematic reviews. Keywords were derivations of the concepts of 'T1DM' and 'sibling'. The combination of keywords, subject headings, and MeSH terms were revised to optimise search results for each database. A librarian was consulted to review the search strategy. The exhaustive list of search strategies can be found in Supplementary material 2. Six electronic databases

(PubMed, CINAHL, PsycINFO, EMBASE, Scopus and ProQuest Theses and Dissertations) were used to search for articles in English language from the respective dates of inception until July 2021. The search for grey literature and unpublished studies (theses and dissertations) was administered through Google Scholar. Finally, a hand search of the reference lists from included studies was conducted to obtain additional relevant studies. No restrictions were imposed on the year of publication. Any form of interviews or surveys delivered individually or group-based in healthcare settings, community, or at home via technology, was included.

### Eligibility criteria

The inclusion and exclusion criteria were as follows:

#### Study type

Both qualitative and quantitative primary studies were included. Qualitative studies with phenomenological, ethnographic, grounded theory, case study and descriptive study designs were included. The included quantitative study type was quantitative descriptive, where information was collected without implementing an intervention. Studies which performed randomised controlled trials or implemented and evaluated any form of interventions were excluded as this review's aim was to adopt an exploratory approach to omit any possibility of manipulation from researchers.

#### Population

Studies which included children below the age of 18 whose siblings are diagnosed with T1DM, including those who were adopted or whose parents married into families where the previously single parents bore offspring (i.e. step-sibling), were included in this review.

#### Phenomena of interest

Studies which documented experiences and needs of siblings who attended to/lived with their sibling with T1DM, and how their attitudes, adjustments, and sibling relationships were affected, were included. Studies which documented family's experiences were also included, as far as the views of siblings can be extracted to understand the impact of the T1DM on the family from the siblings' perspectives.

#### Outcome variables

The outcome variables for qualitative studies included exploring the experiences of siblings of children with T1DM, and how the diagnosis impacted the families from the siblings' perspectives. On the other hand, the outcome for quantitative studies included the emotional difficulties, overall experiences, or maladjustments in children with siblings with T1DM.

The exclusion criteria were: (1) studies containing blood or half-blood siblings (population) aged above 18 years or were suffering themselves with chronic diseases; and (2) studies with children (exposure) suffering from other chronic diseases apart from T1DM.

#### Study selection

Retrieved studies were extracted into EndNote X9 (The EndNote Team, 2013), where duplicates were removed. Title and abstracts were screened for relevance and shortlisted full-text articles were assessed independently by two reviewers for eligibility. Study authors were contacted if the full text of the papers were unavailable.

#### Quality appraisal

Two reviewers independently appraised the included studies using the Mixed Methods Appraisal Tool (MMAT) checklist (Hong et al., 2018). Studies were appraised based on the checklist's questions which were rated 'Yes', 'Can't Tell' and 'No'. All discrepancies were

resolved upon discussion. The quality appraisal of the included studies can be found in Supplementary material 3.

The overall MMAT quality ratings of qualitative and quantitative studies ranged from 65% to 93%, showing an average to high methodological quality. Studies with low appraisal scores were not excluded as the aim of the review was to collate all available evidence to reduce systematic bias and random error (McDonagh et al., 2013). The sole intent of quality appraisal was to facilitate a discussion and not as a means to exclude articles.

*Data extraction and synthesis*

Two reviewers independently extracted the study details (author, year of publication, setting) and descriptive data (study aim, study design, sampling method, data analysis, participant characteristics, emergent themes, and findings), and included the information in a self-designed data extraction form using Microsoft Word. Pilot testing of the data extraction form was performed in 10% of the studies. Interrater agreement was 90% and any discrepancies were resolved through a mutual consensus. No modifications were made to the data extraction tool.

A narrative synthesis approach was used to summarise findings from the studies, using words and texts to elicit conclusions based on the evidence (Popay et al., 2006). Quantitative data analysis was not

possible as the included studies were heterogeneous and varied in methodology (Ioannidis et al., 2008). The data-based convergent qualitative synthesis was used, where quantitative results from each study were converted into a textual summary (Pluye & Hong, 2014). The consolidated qualitative data were then further analysed using Thomas and Harden's thematic synthesis approach (Thomas & Harden, 2008). The synthesis was conducted by two independent authors using a three-step approach: coding of text, establishing descriptive themes, and generating analytical themes. Codes were developed through line-by-line inductive coding, matched and grouped into categories, establishing descriptive themes. Descriptive themes underwent thematic synthesis by re-examining the inferred evidence to the studies' textual data, which generated analytical themes. Analytical themes were finalised when a consensus was reached through discussions.

**Results**

*Search outcomes and study characteristics*

A total of 4929 studies were retrieved initially. After removing duplicates, 2720 titles and abstracts were screened for relevance. Subsequently, 58 full-text articles were assessed for eligibility. A total of 13 articles (10 qualitative, 3 quantitative) were finalised and included in this review. The PRISMA flow diagram is presented in Fig. 1.

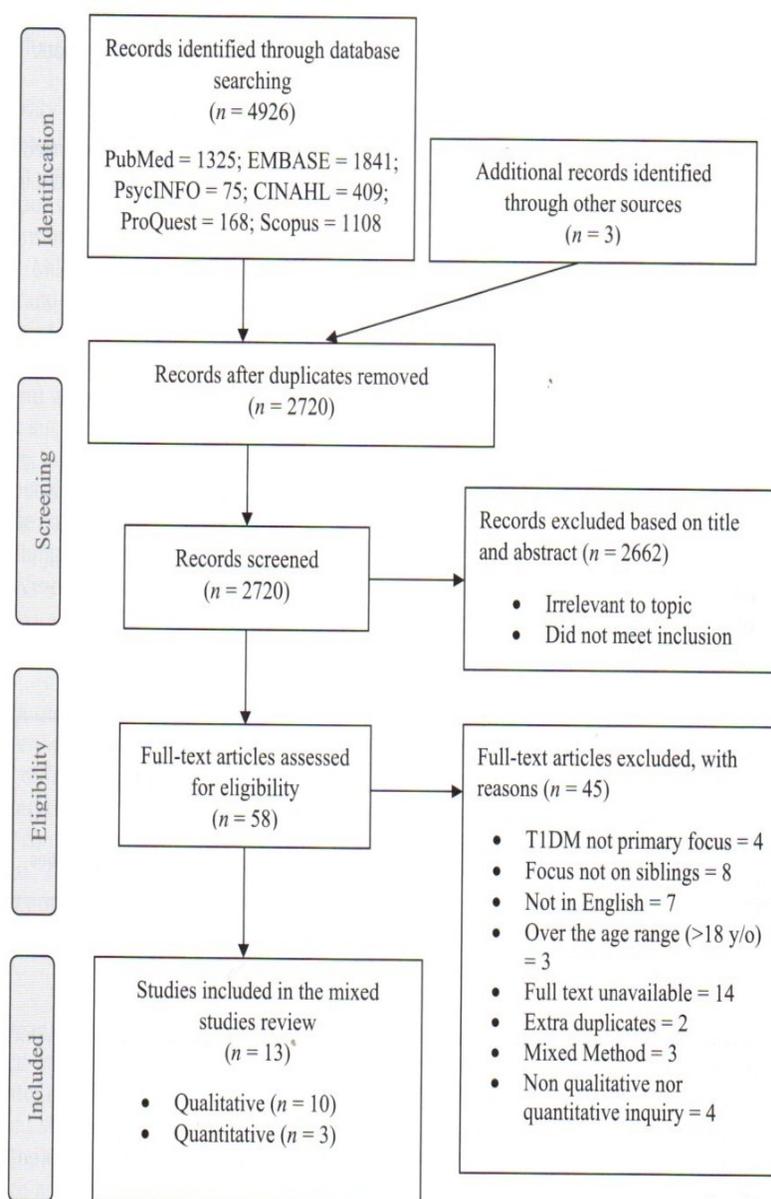


Fig. 1. PRISMA flow chart.

Majority of studies were conducted in Sweden ( $n = 5$ ), followed by the United States ( $n = 4$ ), Australia ( $n = 2$ ), France ( $n = 1$ ) and Turkey ( $n = 1$ ). The sample size of siblings for quantitative studies ranged from 24 to 99, whereas qualitative studies ranged from four to 49. In total, the responses of 287 healthy siblings of children with T1DM were included. Siblings' age ranged from 8 to 18 years, consisting of both younger and older siblings. All three quantitative descriptive studies utilized a comparative design where results of siblings of children with T1DM were compared against their peers with healthy siblings. Self-report questionnaires or surveys were used in the quantitative studies. Qualitative studies adopted a descriptive ( $n = 6$ ), hermeneutic phenomenological ( $n = 3$ ), or exploratory approach ( $n = 1$ ). Data were collected through face-to-face interviews or focus groups. Among the ten qualitative studies, five studies were conducted only with siblings, while the other five were conducted with parents, children with T1DM and their siblings. The detailed information of each study can be found in Supplementary material 4.

Four themes were generated from the synthesis: (1) emotional responses to the sibling's condition, (2) stepping out of comfort zone, (3) changes in family dynamics, and (4) takeaways and a way forward. An overview of the themes and subthemes is presented in Fig. 2. Representative quotes for each theme and subtheme can be found in Supplementary material 5.

*Emotional responses to sibling's condition*

*Fear fuelled by unfamiliarity and lack of knowledge*

As the T1DM diagnosis was unfamiliar to the healthy siblings, they were initially fearful of the disease outcomes and were concerned for their sibling's future. One sibling expressed fear as they had other family members who had succumbed to the same diagnosis: "I thought my brother would die because my grandmother (who had diabetes) died

when dad was 16 years old..." (Sand et al., 2018, p. 103). Another one of them shared, "...if you don't take care of it [T1DM], you could lose a finger, toe, like seriously a leg." (Miller, 2015, p. 14). Generally, older siblings expressed how sad and worried they were to see their younger siblings suffer from T1DM and would rather be the ones suffering instead. One older sibling shared, "I'm scared for her...I don't want anything to happen to her in the future or anything. I wish I can take over her illness." (Herrman, 2010, p. 432).

Witnessing their sibling with T1DM undergo regular insulin treatment also instilled a sense of fear of needles and pain among healthy siblings. In four studies, siblings of children with T1DM expressed how intimidated they were by a needle's sharp end, and often associated T1DM with pain: "There's a lot of pain with diabetes." (Herrman, 2010, p. 431), and "Yah, I hate needles, dude... they stick a needle like that big into him (indicates size with fingers), it's scary!" (Miller, 2015, p. 10).

The lack of knowledge of T1DM and management techniques led to confusion, misconceptions and more fear (Castro et al., 2009). Compulsory school attendance caused siblings to miss out on hospital visits, contributing to the lack of knowledge of T1DM. One sibling shared the confusion he faced towards T1DM: "... I knew nothing about it, didn't have a clue about it, a bit confused" (Loos & Kelly, 2006, p. 60). This lack of knowledge caused siblings to envision the pain from insulin treatment if they develop T1DM in future. Siblings of children with T1DM also shared a fear of developing T1DM themselves: "I did at the beginning and everything and I just didn't want to think about having diabetes myself." (Loos & Kelly, 2006, p. 65), and "I would like to learn how to take care of myself. How to, um, not struggle when I get tests or insulin, and I gotta get used to shots." (Miller, 2015, p. 9).

*Feelings of anger and jealousy*

A handful of studies ( $n = 4$ ) reported that children felt bitter whenever their sibling with T1DM exhibited ignorance or took advantage of

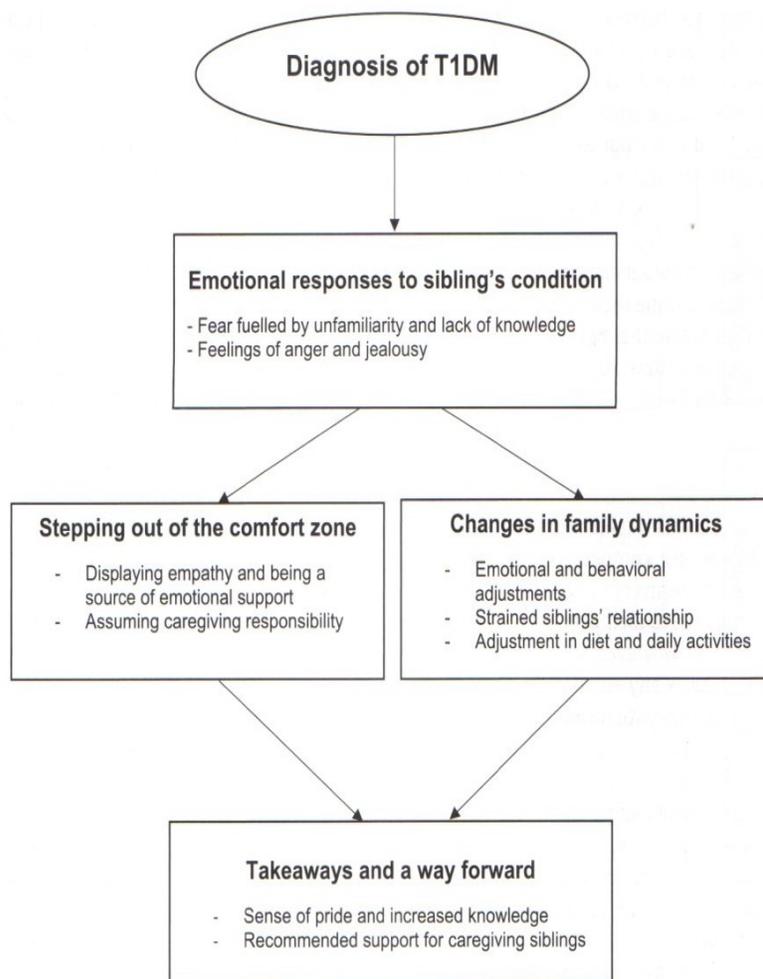


Fig. 2. Overview of themes and subthemes.

the illness. Their unhappiness was demonstrated in the following statement: “She kind of milks the system (imitating youth with T1DM) ... ‘I’m sick’, ‘I can’t do this’, or ‘I can’t [be]cause I’m not feeling good’.” (Miller, 2015, p. 11). Additionally, siblings felt invisible, and they noted how their parents were more forgiving towards their sibling with T1DM, causing feelings of jealousy to arise (Castro et al., 2009). One child shared how their parents were more biased towards the sibling with T1DM: “Yeah, he gets more of Mommy and Daddy when he’s sick, that stinks.” (Herrman, 2010, p. 432).

#### *Stepping out of comfort zone*

##### *Displaying empathy and being a source of emotional support*

Three studies showed how children displayed understanding towards their sibling with T1DM; they tried to be adaptive and refrained from getting angry, knowing the frustrations of insulin injections and lifestyle changes that their sibling with T1DM had to undergo (Wennick & Huus, 2012). One sibling shared how he provided emotional support: “I sit her on my lap, hugging her and comforting her whenever she scared of the injection.” (Loos & Kelly, 2006, p. 62). Lifestyle changes involved restrictions on certain food consumption and activities. One sibling shared how he tried to find alternative food: “Sometimes someone asks if I want this [treat] and [she] can’t have some... I say, do you have a fruit roll up or something like that, just so [she] can have it...” (Miller, 2015, p. 15). Similarly, having T1DM restricts various daily activities. Siblings recognised that their sibling with T1DM could not partake in certain childhood activities and they tend to avoid those activities for the sake of their sibling.

##### *Assuming caregiving responsibility*

When parents were unavailable, some siblings would take on the role of the primary caregiver (Wennick et al., 2009). Older siblings tend to naturally assume responsibility for their sibling’s wellbeing: “I am the oldest... [it is] my responsibility to help out and make sure she [sister with T1DM] blood tests...” (Miller, 2015, p. 8) and “I like watching out for him... it shows I am older and I can do it.” (Herrman, 2010, p. 434). Children were constantly worried about the whereabouts of their sibling with T1DM and always had to keep a lookout for them. One sibling expressed feeling worried and accompanied the sibling with T1DM around: “...I follow him back out in the woods, just in case something goes wrong...” (Faulkner, 1996, p. 89). This responsibility extended not only to the T1DM regulation, but also to household chores. One of the siblings reportedly performed the daily routine their parents did at home: “...I had to do more chores, things my mother normally does... so that she can focus on my sister” (Wennick & Huus, 2012, p. 90).

#### *Changes in family dynamics*

##### *Emotional and behavioural adjustments*

Younger siblings of children with T1DM tend to experience greater emotional and behavioural difficulties; competitiveness and lower self-concept scores were observed in terms of in-school status, happiness and outlook towards life compared to their peers with healthy siblings (Ferrari, 1987; Sand et al., 2018). However, Sleeman et al. (2010) documented that siblings did not report any emotional or behavioural maladjustments compared to their peers with healthy siblings.

##### *Strained sibling relationships*

Due to the strict diabetes management regime and severity of T1DM, parental attention was focused on the child with T1DM. In three studies, children found it tough to interact with their sibling with T1DM. One sibling expressed how distant she was from her sibling with T1DM: “We’ve grown farther apart [be]cause now we fight over the diabetes. I keep on telling him what to and he don’t listen to me.” (Herrman, 2010, p. 432). Having limited outlet to share their frustrations and lack of parental attention made siblings independent, especially in terms of

decision-making and findings ways to understand T1DM. Over time, some children gradually understood the reason behind their parents’ focus on their sibling with T1DM and even actively learned more about T1DM. One sibling shared how he was more understanding towards his sibling: “... it was all about my brother, to begin with... but then when I thought about it, I understood why” (Wennick & Hallström, 2006, p. 379).

##### *Adjustment in diet and daily activities*

Siblings in most studies ( $n = 5$ ) reported changes in dietary and daily routines. Sleeman et al. (2010) found that the changes in eating habits and adopting a healthy diet improved eating behaviour among siblings of children with T1DM. Siblings shared how their families ate healthier food and adjusted mealtimes: “We all drink diet soda...no chocolate cake...no sugar” (Herrman, 2010, p. 432) and “...if my brother has to eat at 5 o’clock, well then we all eat at 5 o’clock.” (Wennick & Hallström, 2006, p. 381). This strict diet plan did not result in any eating disorder among siblings when compared to their peers (Akgül et al., 2018). Additionally, daily childhood activities were disrupted and monitored. One child stated how his sibling with T1DM could not enjoy sleepovers due to T1DM: “She can’t go to sleepovers and stuff...she has to give herself needles...so I decided to forgo them too... I don’t want her to feel left out” (Herrman, 2010, p. 431).

##### *Takeaways and a way forward*

##### *Sense of pride and increased knowledge*

Most siblings felt a sense of pride towards their sibling with T1DM for persevering with managing diabetes. As reported by one sibling, “I am proud of her with how she has dealt with the diabetes and stuff, I think it’s pretty cool.” (Miller, 2015, p. 12). Similarly, they noted how much their siblings with T1DM grew to be more independent. One of them perceived their sibling with T1DM to be more mature than friends of the same age: “...At the same time he has ... become a bit different ... older in some way. He takes responsibility and so on...” (Wennick & Huus, 2012, p. 90).

The increase in nutrition- and medical-related knowledge were stated mainly in three studies, where siblings gradually learned how to count carbohydrates (Akgül et al., 2018). This increase in knowledge built siblings’ confidence and alleviated their fears [38]. One sibling found joy in learning about T1DM: “It is quite fun to learn about diabetes...” (Wennick & Hallström, 2007, p. 304).

##### *Recommended support for caregiving siblings*

With first-hand caregiving experiences, some siblings proposed recommendations that could be utilized in the future families with T1DM children. One expressed their wish to be included in hospital visits: “Like, what’ll I do if [brother with T1DM], like, passes out or something? I want to know what to be able to do...” (Miller, 2015, p. 8). Additionally, other siblings hoped for more positive support from healthcare providers. Receiving adequate informative resources, helplines, and emotional support from healthcare providers is crucial in managing the emotional well-being of caregiving siblings. One sibling expressed that “I think nurses should talk to us... so that we can help our siblings and parents...I often feel ignored during clinic visits...” (Herrman, 2010).

## **Discussion**

This review consolidated 13 studies on the experiences and needs of children with siblings diagnosed with T1DM. The review highlighted siblings’ initial reactions to the diagnosis, subsequent emotional responses, changes in personal growth and family dynamics, personal takeaways and supportive recommendations.

The initial reactions of affected siblings demonstrated how a child’s T1DM diagnosis affected them. The children felt helpless and overwhelmed with the diagnosis of their siblings with T1DM. This finding is

similar to a previous study, which stated that there was a lack of support caused siblings of children with chronic illness to feel powerless, resulting in psychological trauma (Lerwick, 2016). This trauma led to fear that made it difficult for children to accept their sibling's diagnosis, as demonstrated in our findings. The lack of knowledge around T1DM among caregiving siblings may further amplify their lack of control, and this could lead to misconceptions and irrational fear. Therefore, interventions that are more family-centred approach should be adopted for educating on T1DM, and should include both parents, the diagnosed child, and siblings as well. This will not only allay their fears but can also increase awareness and T1DM knowledge among siblings to enable them to support their family better.

As a result of receiving less parental attention, the siblings in this review developed jealousy and anger despite feeling worried and sorry about their sibling with T1DM. This finding is similar to another study on siblings caring for those with asthma and cystic fibrosis (Derouin & Jessee, 1996). Congruent to our review, research have shown that the lack of parental attention was found to exhibit greater attention-seeking behaviours in siblings of children with chronic illness in previous literature (Tregidgo & Elander, 2019). Younger siblings have been found to be more likely to experience emotional difficulties, possibly due to a lack of socio-emotional development (Tregidgo & Elander, 2019). Younger siblings have also been shown to have a tendency to exhibit greater temper tantrums and emotional problems than older siblings (Daniels et al., 2012). Though not explicit in this review, the lack of parental attention might have a greater impact on younger siblings where they are unable to express their emotions appropriately and thus should be further examined in future. Older siblings in this review were found to understand better and display empathy to their sibling with T1DM as they were found to naturally assume caregiving responsibility of their younger sibling with T1DM. These findings concur with existing literature (Akgül et al., 2018), therefore, family support services should consider providing individualized behavioural and emotional interventions for younger siblings, and more supportive interventions for older caregiving siblings of children with T1DM.

In this review, siblings provided emotional support and assumed responsibility of care giving for their siblings with T1DM. Similar to a previous study, older siblings were more mature and responsible in their caregiving duties when their parents were away due to work commitments (Lin & Wu, 2019). These findings highlight that with more responsibilities, older siblings may also gain independence and better decision-making skills as shown in a few studies in this review. Meanwhile, little is mentioned about the provision of emotional support and caregiving responsibility among younger siblings of T1DM children in this review. Therefore, future studies should specifically include an inclusive sample of both younger and older siblings for accurate documentation of the adaptations made by them.

Changes in family dynamics were inevitable after the diagnosis of T1DM as reported by siblings in this review. Similar other studies, lifestyle modifications such as dietary restrictions were found to be necessary for the family to manage T1DM in previous literature (Gonder-Frederick, 2014). A close-knit sibling relationship was found to encourage positive diabetes management adjustments both in this review and in another study (McHale et al., 2012). Therefore, family-centred programmes can be proposed and further developed to promote healthy living among families of children with T1DM while bringing the family closer. However, future research should consider examining the lifestyle modifications and their influence on family members' health before implementing such recommendations in diabetic management programmes.

Lastly, siblings in this review wished to be more involved during hospital visits to care for their sibling with T1DM. They would like to receive more knowledge-based content catered to their needs and be educated on how they can specifically support their siblings and family. A previous study had also reported that children caring for siblings diagnosed with other chronic diseases were excluded from hospital visits

because of various reasons, such as hospital protocols, at school or attended other scheduled activities (Tsimicalis et al., 2018). Similarly, as the diagnosis of the sick sibling has long term ramifications for the entire family, the siblings of the sick child have been found to face unique challenges. Hence, it is necessary to ensure sibling involvement in the care plan of T1DM paediatric patients.

#### *Strengths and limitations*

A strength of this review is that its findings were based on the siblings' first-hand experiences, a population underrepresented in the current literature. Furthermore, the quality appraisal for the included studies ranged from moderate to good quality, thus contributing to this review's overall quality and validity (Creswell & Miller, 2000). A major limitation of this review is the broad age inclusion (8 to 18 years) and the lack of differentiation of older and younger siblings' experiences in the included studies. This may result in data heterogeneity as healthy siblings at different developmental stage or birth order will have different developmental needs, perceived role, and understanding of the disease and management. One limitation of this review is the restriction of including only articles published in English thus could have potentially caused language bias (Morrison et al., 2012). Another limitation is the inclusion of studies conducted in developed countries in this review thus, the findings may not reflect those from developing countries where insulin treatment is not readily available.

#### *Future implications*

Policymakers and stakeholders can utilise this review's findings to develop and improve current support programmes for children with T1DM and their families. Healthcare providers and researchers should adopt and evaluate interventions that are more family-centred approach by including siblings in the care plan of T1DM paediatric patients. The needs and recommendations made by the siblings of T1DM paediatric patients serve as an impetus for healthcare policy makers to develop and implement a family-inclusive informative and supportive programmes so that siblings can be equipped with adequate knowledge and skills to assist with caring for their T1DM siblings to reduce the caregiver burden of their parents. Moreover, healthcare professionals should also provide interventions that assist and support the siblings of children with T1DM, who are themselves in the critical developmental stage, especially in terms of adapting and coping to ensure positive social, emotional, and behavioural development of younger siblings of T1DM paediatric patients. Future primary quantitative and qualitative studies can also consider exploring on types of interventions that are preferred by these siblings.

It is recommended for future studies to differentiate their findings based on few factors such as age of the siblings and whether it is an older or younger sibling who have diabetes, how sick the child with T1DM, duration since the diagnosis has been confirmed and parenting styles. Additionally, the triangulation of findings by including accounts of children with T1DM could bring insights into siblings' experiences and any changes to sibling relationships over time. Furthermore, there is a need to conduct quantitative longitudinal research examining the attitudes and factors influencing siblings' involvement in the care of T1DM paediatric patients to obtain a holistic understanding of how the diagnosis of T1DM in paediatric patients influences the overall family dynamics. Cultural differences may influence siblings' experiences. Therefore, more studies, qualitative and quantitative, from developing countries and different geographical regions are needed for comparative analysis. Lastly, future studies can consider comparing siblings' experiences of those with different chronic diseases. The future comparative analysis through different contexts can allow the results to be extrapolated accordingly to various countries, cultures, and of different chronic diseases.

## Conclusion

This review focused on the experiences and needs of children with siblings diagnosed with T1DM. The findings shed light on the lack of involvement and support services for siblings. More could be done to help these siblings cope with the caregiving burden and changing dynamics around T1DM. The healthcare providers can provide family-centred care according to the individual needs of siblings and engage them in the care of a sibling with T1DM.

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## Data availability statement

All the data have been provided via supplementary files. Any further information can be requested from the corresponding author via email upon reasonable request.

## Authors' contributions

**Ms Kathlynn Chan:** Conceptualization, data curation, formal analysis, writing the original draft, review and editing of the manuscript. **Dr Shefaly Shorey:** Supervision, formal analysis, writing the original draft, review and editing of the manuscript.

Both authors were responsible for the finalized manuscript. Both authors have contributed significantly and are in agreement with the contents of the manuscript.

## Declaration of Competing Interest

The Authors declare that there is no conflict of interest.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pedn.2021.12.002>.

## References

- Akgül, S., Alikashioglu, A., Özön, A., Gönç, N., Düzçeker, Y., Örs, S., ... Kanbur, N. (2018). Can having a sibling with type 1 diabetes cause disordered eating behaviors? *Journal of Pediatric Endocrinology and Metabolism*, 31(7), 711–716. <https://doi.org/10.1515/jpem-2017-0533>.
- Almeida, F., Faria, D., & Queirós, A. (2017). Strengths and limitations of qualitative and quantitative research methods. *European Journal of Education Studies*, 3, 369–387. <https://doi.org/10.5281/zenodo.887089>.
- Begg, I. (2016). The family impact of a child's type 1 diabetes diagnosis: A systematic review: P463. *Diabetic Medicine*, 33. <https://doi.org/10.1111/scs.12140>.
- Castro, D., Malivoir, S., Martin, D., Gagnayre, R., & Robert, J. (2009). Siblings of diabetes type 1 children: Impact of illness and treatment on psychological functioning of brothers and sisters. Implications for therapeutic patient education. *Production Engineering*, 1, 13–19. <https://doi.org/10.1051/tpe/2009004>.
- Cherubini, V., Gesuita, R., Bonfanti, R., Franzese, A., Frongia, A. P., Iafusco, D., ... Carle, F. (2014). Health-related quality of life and treatment preferences in adolescents with type 1 diabetes. The VIPKIDS study. *Acta Diabetologica*, 51(1), 43–51. <https://doi.org/10.1007/s00592-013-0466-x>.
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124–130. [https://doi.org/10.1207/s15430421tip3903\\_2](https://doi.org/10.1207/s15430421tip3903_2).
- Daniels, E., Mandelco, B., & Luthy, K. E. (2012). Assessment, management, and prevention of childhood temper tantrums. *Journal of the American Academy of Nurse Practitioners*, 24(10), 569–573. <https://doi.org/10.1111/j.1745-7599.2012.00755.x>.
- Derouin, D., & Jessee, P. O. (1996). Impact of a chronic illness in childhood: Siblings' perceptions. *Issues in Comprehensive Pediatric Nursing*, 19(2), 135–147. <https://doi.org/10.3109/01460869609038053>.
- Dinleyici, M., & Dağlı, F.Ş. (2018). Evaluation of quality of life of healthy siblings of children with chronic disease. *Turkish Archives of Pediatrics*, 53(4), 205. <https://doi.org/10.4274/balkanmedj.galenos.2019.2019.7.142>.
- Dougherty, J. P. (2015). The experience of siblings of children with type 1 diabetes. *Pediatric Nursing*, 41(6), 279–281 (305).
- Driscoll, K. A., Raymond, J., Naranjo, D., & Patton, S. R. (2016). Fear of hypoglycemia in children and adolescents and their parents with type 1 diabetes. *Current Diabetes Reports*, 16(8), 1–9. <https://doi.org/10.1007/s11892-016-0762-2>.
- East, P. L. (2010). Children's provision of family caregiving: Benefit or burden? *Child Development Perspectives*, 4(1), 55–61. <https://doi.org/10.1111/j.1750-8606.2009.00118.x>.
- Faulkner, M. S. (1996). Family responses to children with diabetes and their influence on self-care. *Journal of Pediatric Nursing*, 11(2), 82–93. [https://doi.org/10.1016/S0882-5963\(96\)80065-0](https://doi.org/10.1016/S0882-5963(96)80065-0).
- Ferrari, M. (1987). The diabetic child and well sibling: Risks to the well child's self-concept. *Children's Health Care*, 15(3), 141–148. <https://doi.org/10.1080/02739618709514760>.
- Gan, L. L., Lum, A., Wakefield, C. E., Nandakumar, B., & Fardell, J. E. (2017). School experiences of siblings of children with chronic illness: A systematic literature review. *Journal of Pediatric Nursing*, 33, 23–32. <https://doi.org/10.1016/j.pedn.2016.11.007>.
- Gonder-Frederick, L. (2014). Lifestyle modifications in the management of type 1 diabetes: Still relevant after all these years? *Diabetes Technology & Therapeutics*, 16(11), 695–698. <https://doi.org/10.1089/dia.2014.0175>.
- Hassouneh, O., Nsour, M., Khuan, L., & Al-Oran, H. M. (2020). Parental stress among parents of children with type 1 diabetes mellitus: A review. *Malaysian Journal of Medicine and Health Sciences*, 16(2), 248–253.
- Herrman, J. W. (2010). Siblings' perceptions of the costs and rewards of diabetes and its treatment. *Journal of Pediatric Nursing*, 25(5), 428–437. <https://doi.org/10.1016/j.pedn.2009.07.004>.
- Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., ... Pluye, P. (2018). The mixed methods appraisal tool (MMAT) version 2018 for information professionals and researchers. *Education for Information*, 34(4), 285–291.
- Ioannidis, J. P., Patsopoulos, N. A., & Rothstein, H. R. (2008). Reasons or excuses for avoiding meta-analysis in forest plots. *BMJ (Clinical Research Edition)*, 336(7658), 1413–1415. <https://doi.org/10.1136/bmj.a117>.
- Kimbell, B., Lawton, J., Boughton, C., Hovorka, R., & Rankin, D. (2021). Parents' experiences of caring for a young child with type 1 diabetes: A systematic review and synthesis of qualitative evidence. *BMC Pediatrics*, 21(1), 160. <https://doi.org/10.1186/s12887-021-02569-4>.
- Lefebvre, C., Glanville, J., Briscoe, S., Littlewood, A., Marshall, C., Metzendorf, M. I., ... Thomas, J. (2019). Searching for and selecting studies. *Cochrane handbook for systematic reviews of interventions* (pp. 67–107).
- Lerwick, J. L. (2016). Minimizing pediatric healthcare-induced anxiety and trauma. *World Journal of Clinical Pediatrics*, 5(2), 143. <https://doi.org/10.5409/wjcp.v5.i2.143>.
- Limbers, C. A., & Skipper, S. (2014). Health-related quality of life measurement in siblings of children with physical chronic illness: A systematic review. *Families, Systems & Health*, 32(4), 408–415. <https://doi.org/10.1037/fsh0000077>.
- Lin, I.-F., & Wu, H.-S. (2019). Sibling influences, sibling similarities, and parent care in late life. *Ou Mei Yan Jiu*, 49(1), 45.
- Loos, M., & Kelly, S. (2006). Social well-being of siblings living with a child with diabetes: A qualitative study. *Social Work in Health Care*, 43(4), 53–69. [https://doi.org/10.1300/J010v43n04\\_04](https://doi.org/10.1300/J010v43n04_04).
- Maahs, D. M., West, N. A., Lawrence, J. M., & Mayer-Davis, E. J. (2010). Epidemiology of type 1 diabetes. *Endocrinology and Metabolism Clinics of North America*, 39(3), 481–497. <https://doi.org/10.1016/j.ecl.2010.05.011>.
- McDonagh, M., Peterson, K., Raina, P., Chang, S., & Shekelle, P. (2013). Avoiding bias in selecting studies. *Methods guide for effectiveness and comparative effectiveness reviews [Internet]*.
- McHale, S. M., Updegraff, K. A., & Whiteman, S. D. (2012). Sibling relationships and influences in childhood and adolescence. *Journal of Marriage and Family*, 74(5), 913–930. <https://doi.org/10.1111/j.1741-3737.2012.01011.x>.
- Miller, S. (2015). *The experience of siblings of youth with type 1 diabetes (publication number theses and dissertations. 5868)*. Brigham Young University. <https://scholarsarchive.byu.edu/etd/5868>.
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Group, P. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine*, 6(7), Article e1000097. <https://doi.org/10.1136/bmj.b2535>.
- Morrison, A., Polisena, J., Husereau, D., Moulton, K., Clark, M., Fiander, M., ... Rabb, D. (2012). The effect of English-language restriction on systematic review-based meta-analyses: A systematic review of empirical studies. *International Journal of Technology Assessment in Health Care*, 28(2), 138. <https://doi.org/10.1017/S0266462312000086>.
- Namkung, E. H., Greenberg, J. S., & Mailick, M. R. (2017). Well-being of sibling caregivers: Effects of kinship relationship and race. *The Gerontologist*, 57(4), 626–636. <https://doi.org/10.1093/geront/gnw008>.
- Pluye, P., & Hong, Q. N. (2014). Combining the power of stories and the power of numbers: Mixed methods research and mixed studies reviews. *Annual Review of Public Health*, 35, 29–45. <https://doi.org/10.1146/annurev-publhealth-032013-182440>.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews: A product from the ESRC methods programme. <http://doi.org/10.13140/2.1.1018.4643>.

- Sand, P., Blom, M. D., Forsander, G., & Lundin, C. S. (2018). Family dynamics when a child becomes chronically ill: Impact of type 1 diabetes onset in children and adolescents. *Nordic Psychology, 70*(2), 97–114. <https://doi.org/10.1080/19012276.2017.1362990>.
- Simpson, S., Hanna, P., & Jones, C. J. (2021). A systematic review of parents' experiences of raising a child with type 1 diabetes. *The British Journal of Diabetes, 21*(1), 44–58. <http://doi.org/10.15277/bjd.2021.291>.
- Sleeman, F., Northam, E., Crouch, W., & Cameron, F. (2010). Psychological adjustment of well siblings of children with type 1 diabetes. *Diabetic Medicine, 27*(9), 1084–1087. <https://doi.org/10.1111/j.1464-5491.2010.03041.x>.
- Tariq, S., & Woodman, J. (2013). Using mixed methods in health research. *JRSM Short Reports, 4*(6), 2042533313479197. <https://doi.org/10.1177/2042533313479197>.
- The EndNote Team (2013). *EndNote [computer software]. In (version EndNote X9) [64 bit]. Clarivate.*
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*(1), 1–10. <https://doi.org/10.1186/1471-2288-8-45>.
- Tregidgo, C., & Elander, J. (2019). The invisible child: Sibling experiences of growing up with a brother with severe haemophilia: An interpretative phenomenological analysis. *Haemophilia, 25*(1), 84–91. <https://doi.org/10.1111/hae.13659>.
- Tsimicalis, A., Genest, L., Stevens, B., Ungar, W. J., & Barr, R. (2018). The impact of a childhood cancer diagnosis on the children and siblings' school attendance, performance, and activities: A qualitative descriptive study. *Journal of Pediatric Oncology Nursing, 35*(2), 118–131. <https://doi.org/10.1177/1043454217741875>.
- Wennick, A., & Hallström, I. (2006). Swedish families' lived experience when a child is first diagnosed as having insulin-dependent diabetes mellitus: An ongoing learning process. *Journal of Family Nursing, 12*(4), 368–389. <https://doi.org/10.1177/1074840706296724>.
- Wennick, A., & Hallström, I. (2007). Families' lived experience one year after a child was diagnosed with type 1 diabetes. *Journal of Advanced Nursing, 60*(3), 299–307. <https://doi.org/10.1111/j.1365-2648.2007.04411.x>.
- Wennick, A., & Huus, K. (2012). What it is like being a sibling of a child newly diagnosed with type 1 diabetes: An interview study. *European Diabetes Nursing, 9*(3), 88–92. <https://doi.org/10.1002/edn.213>.
- Wennick, A., Lundqvist, A., & Hallström, I. (2009). Everyday experience of families three years after diagnosis of type 1 diabetes in children: A research paper. *Journal of Pediatric Nursing, 24*(3), 222–230. <https://doi.org/10.1016/j.pedn.2008.02.028>.
- Whittemore, R., Jaser, S., Chao, A., Jang, M., & Grey, M. (2012). Psychological experience of parents of children with type 1 diabetes: A systematic mixed-studies review. *The Diabetes Educator, 38*(4), 562–579. <https://doi.org/10.1177/0145721712445216>.
- Yang, H. -C., Mu, P. -F., Sheng, C. -C., Chen, Y. -W., & Hung, G. -Y. (2016). A systematic review of the experiences of siblings of children with cancer. *Cancer Nursing, 39*(3), E12–E21. <https://doi.org/10.1097/NCC.0000000000000258>.