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A Mixed Research Synthesis: Sibling Experiences when Living with a Young Person with Type 1 Diabetes Mellitus

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ABSTRACT

Youth with type 1 diabetes (T1D) and their families must cope with the rigors of diabetes management which effect all family members, including Sibling. However, most information on Sibling experiences when living with children/adolescents with T1D was published prior to 2000 and comes from parents/teachers rather than Sibling themselves. Therefore, this mixed research synthesis examined and summarized research published since 2000 from 10 articles (2 quantitative, 6 qualitative, 2 mixed methods) meeting inclusion criteria that examined sibling's experiences when living with a young person with T1D. Five themes emerged from the data:

- (1) Sibling perceptions of the experience (how they viewed the situation).
- (2) Sibling knowledge of the condition (who told them and what they knew about T1D).
- (3) Sibling emotional reactions (affect, feelings, moods).
- (4) Sibling behavioral/personality characteristics/outcomes (academic and social effects).
- (5) Sibling interactions with others (what interactions were like with the young person with T1D, family members, or those outside the family).

Health care providers caring for families raising youth with T1D should assess Sibling and provide interventions reflecting their individual experiences related to their perceptions, knowledge, emotions, outcomes, and interactions with others so their development is enhanced.

INTRODUCTION

Type 1 diabetes (T1D), a common chronic childhood disease, is caused by insulin deficiency resulting from destruction of insulin producing pancreatic beta cells ^[1]. Currently there is no cure for T1D; however, youth with T1D and their families must cope with the rigors of diabetes management including adherence to treatment regimens such as providing insulin therapy before eating carbohydrates, monitoring dietary intake, being physically active, and checking blood glucose regularly ^[2].

These management requirements effect all family members, including parents and Sibling. For example, recent studies documenting parent experiences raising youth with T1D suggest they experience loneliness and grief, need emotional support, are afraid of letting the young person go anywhere alone, are concerned about long-term complications, and feel overwhelmed with daily responsibilities ^[3-10]. Early research investigating Sibling of youth with T1D discovered they were impacted by the situation. For example, Ferrari and Adams and colleagues learned these Sibling were at risk of maladjustment ^[11-12]. In addition, Faulkner found Sibling of youth with T1D needed to be vigilant, especially when playing outdoors with the youth or when parents were not

around, and dietary restrictions were disruptive; others were lonesome, jealous, experienced conflicts over dietary restrictions, and confused over emotions experienced^[13-14]. However, research also discovered they functioned similar to Sibling of typically developing children (TDC), and were interested in being part of the management regiment^[15-16]. In addition, Sibling knowledge of diabetes was related to how much they interacted with the young person; those with more knowledge were more likely to have more interactions with the young person^[14].

Indeed, it is important to gain an understanding of sibling experiences when living with a young person with a chronic illness such as T1D. However, most data are from parent/teacher perspectives rather than from sibling perspectives; and most data were gathered before 2000. Therefore, this mixed research synthesis sought to examine and summarize quantitative and qualitative studies written since 2000 discussing sibling experiences when living with a young person who has T1D.

METHOD

This mixed research synthesis followed suggestions offered by Sandelowski, Voils, and Barroso^[17]. Therefore, analyses of quantitative and qualitative designs were combined rather than separated since the purpose was to synthesize knowledge from each type of design about sibling perceptions when living with a young person with T1D. Consequently, we followed Cooper's suggestions and initially defined the problem (creating an integrative review examining sibling perceptions when living with a young person with T1D), then used specific inclusion/exclusion criteria to identify mixed methods, quantitative and qualitative designs focusing on the purpose of the review^[18-19].

An experienced science librarian helped ensure the search was comprehensive, by accessing ERIC, CINAHL, PsychINFO, MEDLINE, and Family & Society Studies Worldwide. Search terms included *brother, sister, sibling, OR child, psychosocial OR psychologist*, adapt*, adjust*, cope, stress, attitude, perce*, experience, know*, learn** combined with *type I diabetes mellitus*. After retrieving reports, reference lists were also examined. Inclusion criteria included full text empirical studies published between 2000 and 2014 and written in English. Sibling needed to be between 4 and 18 years of age as most youth younger than 4 years of age would have difficulty completing questionnaires or responding to interview questions. We only looked at data generated by Sibling younger than 18 because we wanted to focus on experiences of this age group (children and adolescents) rather than an older age group. Since the purpose of the review was to synthesize only sibling data, if Sibling and parents participated in the study, only sibling data were extracted. Books; book chapters; unpublished studies; Sibling older than 18 years of age; results reported for the family as a whole rather than Sibling specifically; intervention outcomes; or articles related to type 2 diabetes (T2D) were excluded. We excluded books, book chapters and unpublished studies because they may not have been peer reviewed; intervention studies were also not used as we sought only to examine Sibling' perceptions of their experience not evaluations of an intervention for Sibling. Finally, we chose not to appraise Sibling of youth with T2D since our purpose was to examine experiences living with a young person with T1D rather than T2D.

RESULTS

The electronic search identified 83 articles. Study authors screened all articles to determine if inclusion criteria were met. Specifically, each article title was noted and then the abstract, and/or the method section examined to identify the age of Sibling, how data were gathered, who provided data, and if sibling data could be extracted from the data. After reaching consensus 10 studies were chosen to be included in the review (2 quantitative, 6 qualitative, 2 mixed methods); 6 were published in nursing journals.

Each article chosen was assessed for validity. The 6 qualitative articles were appraised according to Elliot, Fischer and Rennie, who proposed guidelines for publication of qualitative research^[20]. Evaluation indicated all 6 articles accurately reflected the study purpose, provided interview data to support analysis decisions, described the sample adequately, discussed credibility checks, and were written well. Even though most mentioned study limitations, author values and assumptions related to study purposes were rarely presented^[20]. The 2 quantitative and 2 mixed methods articles were evaluated according to the "Rating System for the Hierarchy of Evidence", suggested by Melnyk and Fineout-Overholt^[21]. There are seven levels of evidence in this rating system; from Level I (strongest evidence; systematic review of meta-analysis of RCTs or evidence-based clinical practice guideless based on systemic RCT reviews) to Level VII (evidence from reports of expert communities and/or opinions of authorities). The articles selected were appraised at Level IV (well-designed case controlled and cohort studies). Cohort studies and case-control studies are observational studies helping evaluate associations between variables of interest. The articles used were primarily cohort studies which used two groups (cohorts) of participants (one group of Sibling living with a young person with T1D and one group not living with a youth with T1D) and then examined these cohorts for differences or relationships between the variables of interest.

Each author then created a table based on studies meeting inclusion criteria that contained author, purpose, design, sample, method, and results. The tables were then compared/contrasted and discussed and organized into a final table^[22]. Refer to Table 1.

Participants came from a variety of countries including Sweden (4 publications), the United States and Australia (2 publications each), and Canada and the United Kingdom (1 publication each). Sample sizes in the qualitative studies ranged from 4 to 10. The quantitative studies had samples of 45 and 99 and the mixed methods studies had samples of 28 and 41.

Examination of study findings revealed five themes. The themes were determined by each author describing the important findings from individual studies and then discussing the themes until reaching consensus. The themes identified included:

- (1) Sibling perceptions of the experience (how they viewed the situation).
- (2) Sibling knowledge of the condition (who told them and what they knew about T1D)
- (3) Sibling emotional reactions (affect, feelings, moods)
- (4) Sibling behavioral/personality characteristics/outcomes (academic and social effects)
- (5) Sibling interactions with others (what interactions were like with the young person with T1D, family members, or those outside the family). These themes are discussed in the following paragraphs.

Sibling living with a young person with T1D had varying perceptions or views about the situation. They perceived their daily routines were interrupted, and reported experiencing dietary restrictions [23, 24]. However, over time Sibling adjusted as they became knowledgeable about insulin, diet, exercise, and potential complications, and as the young person learned to manage the disease and didn't constantly seem ill [23-25]. Other Sibling considered T1D an injury rather than an illness; saw the illness as invisible; and thought the youth with T1D was more mature than friends the same age, yet viewed themselves as powerless regarding the meaning of T1D [24,26]. Sibling with more negative perceptions of the experience had more adjustment difficulties [25].

Sibling' knowledge and understanding of T1D came primarily from parents and by living with the young person [24,27]. However, Sibling reported receiving no formal education about T1D from doctors, nurses or diabetes educators, wanted to be included in classes about T1D, thought learning about T1D was difficult, and the disease would ruin the youth's life [24,27-28].

Sibling knew about basic T1D management [23]. They recognized T1D symptoms including increased thirst and urination, and decreased weight before the diagnosis was confirmed, but didn't understand the purpose of frequent medical visits [24,29]. Sibling were also aware of potential short term consequences of T1D such as weight loss and tiredness, pain, and insulin reactions [23,26,27,29]. In addition, they were cognizant of long term complications, including amputations, dialysis, blindness, and death if the disease was not treated appropriately [23-24].

Sibling reported living with a young person with T1D resulted in negative emotional reactions, including anxiety, sadness, guilt, jealousy, and anger. Their anxiety was related to fear of needles; insufficient knowledge about T1D; worry about the brother/sister's health and possible insulin reactions; and stress about their own potential for developing T1D [23-27,30]. In addition, Hollidge found almost half the Sibling he studied exhibited some depressive symptoms; and brothers/sisters reported experiencing sadness and guilt, and felt sorry for the youth because he/she endured painful procedures, and had restricted diets and eating schedules [24,26,28,30]. Additional Sibling felt jealous/angry because of the attention the young person received from others; or on the other hand, did not report greater emotional maladjustment than norms [24,27,30-31].

Behaviors/personality characteristics reported by Sibling living with a young person with T1D varied. For example, some Sibling did not report any behavioral/emotional dysfunctions compared to Sibling of TDC [31]. However, other Sibling mentioned they experienced increased responsibility and had heightened health awareness [23,25,27,28,30]. In addition, Sibling knew they needed to be more patient with the brother/sister's mood swings, and understood why parents gave the young person more attention [28]. Other Sibling reported there were rewards of living with a child/adolescent who had T1D; the sibling learned the importance of cooperation in caring for others [29]. Investigators also discovered Sibling of youth with T1D scored lower in scholastic competence and global self-worth than Sibling of young people with asthma or TDC; lower than Sibling of TDC on sharing problems and family decisions; and if they rated their behavioral conduct, physical appearance, scholastic competence, and global self-worth low, reported low overall satisfaction with family functioning [32]. In addition, almost half the Sibling Hollidge studied fell below the mean for total self-concept. On the other hand, some Sibling did not report greater behavioral maladjustment or more pro-social behavior than norms [30-31]. Finally, Sibling of youth with T1D were better adjusted than normative data; however, Sibling who were self-critical on the KIDCOPE were more likely to have adjustment difficulties [25]. Other outcomes included Sibling' ability to help manage T1D independently when the youth had an insulin reaction [29].

Living with a young person with T1D impacted Sibling' interactions with others, especially the young person. For example, the disease strengthened sibling relationships when Sibling participated in diabetic management and felt concern for the ill youth [27]. Yet, the disease also strained relationships because of disagreements over T1D management [23,27].

Sibling' interactions with parents were stressed. This is because the relationship changed, or Sibling felt ignored/left out [24,25,27,29]. However, strain between Sibling and parents lessened over time as parents became more comfortable managing T1D and less focused on the child/adolescent, even though Sibling did not discuss their feelings about T1D with parents or other family members [25-26,29,30]. Finally, Sibling felt the family was healthier and closer because of living with a young person with T1D [23].

DISCUSSION

Examination of articles used in this mixed research synthesis revealed 5 themes related to experiences of Sibling of youth with T1D. The themes are sibling perceptions of the situation; sibling knowledge of the condition; sibling emotional reactions to

the condition; sibling behavioral/personality characteristics/outcomes; and sibling interactions with others.

Sibling perceptions focused on how their daily routines were interrupted and especially mentioned experiencing dietary restrictions. These findings are similar to other research. For example, earlier work by Minagawa discovered Sibling of young people with T1D experienced conflicts over dietary restrictions, and Sibling of youth with cancer perceived cancer management and treatment regimens negatively [14,33-34]. However, perceptions of Sibling of youth with developmental disabilities often related to the young person's personality characteristics rather than to perceptions of the disability or treatment requirements [35-39]. Finally, some Sibling of youth with T1D viewed the disability/condition as an injury rather than an illness, and the illness as invisible, similar to perceptions of Sibling of youth with autism [37].

We also discovered Sibling of youth with T1D knew about T1D and many learned information from parents. These findings are similar to recent studies examining Sibling of youth with developmental disabilities or cancer [33,35,38,40,41]. However, we also learned Sibling reported not receiving information about T1D from doctors, nurses or diabetes educators, and did not know about the need for routine medical checkups [24,27,29]. Additionally, even though some Sibling of youth with T1D knew about the disease, they also wanted to be more involved in learning about T1D. Interestingly, in the 1990s, Minagawa discovered sibling knowledge of diabetes was related to how much Sibling interacted with the young person; those who knew more were more likely to interact more [14].

Sibling' emotional reactions were most commonly negative and included anxiety, sadness, guilt, jealousy, worry, sadness, depression, and anger. Earlier research with Sibling of youth with T1D found similar results, as did research on Sibling living with a young person with developmental disabilities or other chronic illnesses [11,12,14,31,35,38,42-50]. In addition, Minagawa discovered these Sibling experienced stress about their own potential for developing T1D; and emotions of Sibling in this review were similar to Sibling of TDC [14-15].

Interestingly, living with a young person with T1D effected Sibling' behaviors and personality outcomes. Similar to other studies examining Sibling of youth with developmental disabilities or cancer, many Sibling of youth with T1D reported positive outcomes including assuming a healthier lifestyle and becoming more caring, kind, helpful, patient, cooperative, mature, understanding, and compassionate [51-56]. Recent research found Sibling of youth with T1D, as well as those who lived with a young person with a chronic illness or developmental disability reported assuming increased responsibility [34,36,53]. On the other hand, there were also negative outcomes for these Sibling, including problems in academics, lower self-concept, lower self-worth or psychosomatic symptoms, similar to Sibling of youth with cancer [48,57,58].

Interactions these Sibling had with the young person with T1D was effected. As seen in Sibling of young people with cancer, Sibling of youth with T1D were concerned about the youth's health/wellbeing, and reported relationship stress was caused by required medical management [33,34], the situation, or family functioning [46,55]. However, in contrast to Sibling of youth with cancer who did not want to do anything to upset the young person, Sibling of youth with T1D sometimes fought with the youth [34].

Interactions Sibling of youth with T1D had with parents were also impacted by the illness. They reported often receiving less attention from parents, like other studies examining Sibling of youth with developmental disabilities or cancer [34,38,48,53]. Similarly, Sibling of youth with chronic conditions (cancer, cystic fibrosis, diabetes, spina bifida, and developmental disabilities) reported there was less time and opportunity for communication with family members due to the condition which likely also impacted interactions with parents [59]. On the other hand, Williams and colleagues learned family closeness was a positive outcome of living with a young person with a chronic illness, similar to Hermann's study [23,42].

Finally, Sibling of youth with T1D did not mention how interactions with friends were impacted by the situation; however, Sibling of youth with developmental disabilities or cancer did note either negative or positive effects on friends [33,34,38,45,48,49,52,60].

IMPLICATIONS

Indeed, living with a child/adolescent who has T1D is life-changing for Sibling. Therefore, health care providers need to always assess sibling perceptions of T1D and then provide specific interventions. For example, it might be useful to verify to Sibling that the illness causes changes in family life, and may have negative consequences and inconvenient treatments. It may also be important to acknowledge sibling's life is effected and even though the young person appears healthy and evidence of T1D is not readily visible, it will impact the youth's life forever.

Health care providers working with families raising a young person with T1D should also be aware of sibling knowledge and provide information as needed to explain the disease and treatment modalities or clarify misunderstandings, answer questions honestly, and allow Sibling to become involved if appropriate. Parents may need assistance talking to Sibling about T1D since many Sibling learned about T1D from parents, but if parents are uncomfortable talking with Sibling, providers should learn more about why that is the case, and assist them become more comfortable.

It is also important to acknowledge sibling emotional reactions might often be negative. Therefore, it would be essential to help Sibling understand these emotions are common; and then implement preventative interventions, such as sibling support groups or information sessions. In addition, health care providers and parents should spend time with Sibling allaying fears and

worries, discussing sibling experiences, and helping them understand how their emotions might be overcome or channeled to be less negative. Finally, positive emotions should be applauded and encouraged.

Since many behavioral and personality outcomes seen in Sibling of youth T1D were positive, these outcomes need supporting. Although Sibling reported assuming more responsibilities, parents should not ask Sibling to assume more responsibilities than reasonable, and explain why they may sometimes be asked to assume those responsibilities. The negative outcomes related to academics, self-concept, self-worth, or psychosomatic symptoms may require referral to suitable academic or psychological counseling, and parents encouraged to provide appropriate academic assistance and discuss sibling academic progress with teachers, if needed.

Providers also need to be aware interactions Sibling of youth with T1D develop with others are effected by the situation. It is true interactions with the young person reflected care and concern, but conflict and rivalry are normal and sometimes cannot be avoided. Since Sibling reported interactions with parents were effected, and they perceived receiving less attention than the young person with T1D, parents should be apprised of this situation and made aware of the importance of spending quality time with the sibling.

Finally, health care providers can help Sibling develop positive interactions with other young people, including those also living with a child/adolescent with T1D, as sharing thoughts and feelings with others in the same situation can be helpful as Sibling learn they are not alone in their feelings^[61,62]. If negative interactions with friends occur because friends do not understand sibling experiences, providers can assist Sibling share information with friends about the youth so friends become more supportive and understanding.

CONCLUSION

This mixed research synthesis examined empirical studies published between 2000 and 2014 that examined sibling experiences when living with a young person with T1D. Clearly, Sibling of a child/adolescent with T1D are effected by the situation; some are continually challenged and have difficulties, whereas others adapt to the situation.

This synthesis fills a gap in the literature, but there are limitations. First, since this paper examined studies published from 2000 to 2014, research published before 2000 was excluded. In addition, different research questions were asked (explorations of sibling experiences (some over time), assessments, and group comparisons); participants lived in 5 countries; and were between 4 and 18 years of age. Qualitative, quantitative, or mixed method designs were synthesized and data obtained through interviews or questionnaires. Designs were primarily cross sectional rather than longitudinal; but the four Wennick articles reviewed^[24,26,28,29] are, according to their titles, conducted with the same participants but at different points in time, and conceptually, could be considered longitudinal studies. In addition, the articles did not provide much information as to how long the young person had been living with T1D nor how well the young person managed T1D over time. Consequently, generalizations of the quantitative and mixed methods studies and the transferability of the qualitative studies are limited and further research is warranted.

Therefore, future research should continue exploring sibling perceptions of living with a young person with T1D. For example, gathering data from these Sibling from various demographics (ethnic background; family type; educational levels; socioeconomic status), and then evaluating perceptions across variables might be useful. Investigating parents' perceptions of sibling experiences and then comparing those responses with sibling perceptions may also be worthwhile. In addition, gathering information from Sibling living in suburban or rural areas where services may not be available, or more thoroughly looking at differences in perceptions according to gender, age, and birth order, might add to our understanding. Further recommendations include using Sibling of young people with other chronic conditions/disabilities or those living with T1D as participants so comparisons are possible. Finally, gathering data longitudinally, and examining Sibling with positive experiences in order to help explain why some have fewer difficulties than others in adjusting to the situation may also be useful.

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