

# Constant Vigilance: Mothers' Work Parenting Young Children With Type 1 Diabetes

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Little is known about the experiences of mothers raising young children with type 1 diabetes. The purpose of this study was to describe the day-to-day experiences of mothers ( $N = 28$ ) raising young children under 4 years of age with type 1 diabetes. Descriptive, naturalistic inquiry principles were used to interview subjects, as well as to manage and analyze the data. The mothers reported using the management behavior of constant vigilance. Their concerns about hypoglycemia and providing competent care reflected the interplay between their fears and profound sense of responsibility for managing the disease. Mothers reported having to learn the management behaviors and to occasionally adjust the day-to-day management when either severe hypoglycemia or developmental milestones occurred. Although mothers initially had feelings of incompetence with the care they provided, with time, they became very skilled. There were also reports of limited access to babysitting, child care, or respite services. The intensity of their constant vigilance associated with their concerns, responsibility, and lack of supports resulted in some mothers having physical and/or emotional problems. The findings of the study highlight the importance of identifying family and/or community resources that may provide mothers with support that could reduce some of the tremendous stress and burden of responsibility experienced after diagnosis of diabetes.

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**T**YPE 1 DIABETES is the most common metabolic disorder in children and affects almost 2 in 1000 children under the age of 20 years (American Diabetes Association [ADA], 1999b). Approximately 13,171 new cases are identified each year in individuals under the age of 19 years. Over the last 20 years the incidence of type 1 diabetes in children under 5 years of age has increased. The cause of the age-specific increase is unknown. Although there are presently no data from the United States, Europe has recently reported a pooled 6% annual incidence increase (4%-9%) of type 1 diabetes for 0- to 4-year-olds from 1989-1994 (EURODIAB Collaborative Group, 2000).

Parenting a child with type 1 diabetes is challenging, particularly when the child is very young (Kushion, Salisbury, Seitz, & Wilson, 1991). In addition to the normal challenges of promoting physical, cognitive, and socioemotional growth and development, parents must face the complex management of the disease, including blood glucose monitoring, insulin administration, and meal planning (Boland & Grey, 2000; Canam, 1993).

With young children, these tasks are made even more complex by the administration and adjustment of small doses of insulin, finicky eating, and difficulty recognizing early symptoms of hypoglycemia (Ahern & Grey, 1996). Yet, little is known

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*This study was partially funded by National Institutes of Health National Institute of Nursing Research grants F31 NR07232-01 and F32NR07501-02 for manuscript writing support.*

*The authors thank Dr Kathleen Knafl, Professor at Yale University School of Nursing, for her contribution in the development and refinement of this paper. The authors also thank Bill Storandt for his editorial expertise. Most of all, the authors would like to thank the mothers who graciously participated in this study.*

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*0882-5963/03/1801-0004\$30.00/0*

*doi:10.1053/jpdn.2003.4*

about how parents deal with both the day-to-day management of the disease and the developmental needs.

The complex caretaking responsibilities can create tremendous stress (Sullivan-Bolyai, Deatrck, Gruppuso, Tamborlane, & Grey, 2002). Parents may become so burdened with concerns related to the day-to-day illness management, especially preventing episodes of hypoglycemia, that they lose sight of normal development and psychosocial interaction, as well as other family-related needs. It is critical to understand the day-to-day experiences of parents in order to provide appropriate guidance and support.

The purpose of this study was to provide a detailed description of day-to-day management experiences of mothers raising young children under 4 years of age with type 1 diabetes. This information may help health care providers offer more precise management guidance for parents with children in this age group.

### LITERATURE REVIEW

Diabetes management presents parents with a unique set of challenges that are intensified when the child is very young. Only one small qualitative study has explored the experience of parenting very young children with type 1 diabetes (Hatton, Canam, Thorne, & Hughes, 1995). Eight 2-parent families who had a young child diagnosed with diabetes were interviewed over a 5-month period. Parents described 3 phases of care: initial diagnosis and hospitalization, adapting to the home environment after discharge, and providing ongoing care. They did not, however, explore specific concerns of the illness-related care, the magnitude of the work required, how the parents learned to eventually manage the day-to-day care, or what types of supports were used to help lessen the burden of care.

Parents of young children with diabetes have reported having concerns regarding provision and quality of care (i.e., perceptions of competence) during the early months after diagnosis (Hatton et al., 1995). Being able to interpret blood glucose levels correctly and manage them appropriately was identified as especially stressful. These findings were similar to those reported by mothers of young children with other chronic conditions (Hy-movich & Baker, 1985; Pinelli, 1981; Stevens, 1994). For example, mothers of infants with congenital heart disease or those in need of home cardiorespiratory monitors were also concerned about being competent in providing adequate care

and recognizing signs of either medical or emotional distress (Pinelli, 1981; Stevens, 1994). However, none of these studies explored the process parents went through to become competent in their children's care.

A common concern identified by parents of young children diagnosed with type 1 diabetes is hypoglycemia (Hatton et al., 1995; Sullivan-Bolyai et al., 2002). Similarly, parents have reported feeling concerned, stressed, and frustrated by the responsibility of ongoing monitoring for hypoglycemia and giving injections over time (Banion, Miles, & Carter, 1983; Betschart, 1988; Parker, Swift, Botha, & Raymond, 1994). Mothers of older children did eventually become less concerned with these management issues the longer the child had the disease. However, the complexity of current treatment recommendations from the Diabetes Control and Complications Trial (DCCT) Research Group (1993) has increased in recent years and includes closer monitoring of glucose and more frequent administration of insulin for elevated glucose levels (ADA, 2001a). Strict glycemic control may result in more episodes of hypoglycemia. This side effect has the potential for increasing parental anxiety, especially when children are very young and cannot easily communicate how they are feeling (ADA, 1999). It is not known how the DCCT guidelines affect the parents' daily management workload or their concerns regarding hypoglycemia when the child is very young.

Day-to-day management of diabetes can be especially complicated and challenging during the toddler and preschool years. Along with the management demands required by the DCCT guidelines, it is normal during these two developmental stages for the child to assert his or her control. Daily tasks such as frequent glucose monitoring and insulin injections may become more complicated for the parents to manage (Bland & Wood, 1991; Savinetti-Rose, 1994). These management and behavioral tasks may also interfere with the child's opportunities for normal developmental experiences. No studies could be found that addressed these issues in young children with type 1 diabetes.

Parents of children with chronic conditions who report having adequate social support also perceive less stress in their lives (Eiser, Havermans, Kirby, Eiser, & Pancer, 1993; Heaman, 1995; O'Brien, 2001; Sterling, Jones, Johnson, & Bowen, 1996). Although the literature describes mothers of children with a variety of chronic conditions using social supports to help manage their children's

needs, the bulk of the burden of care rests on the mothers (Faulkner, 1996; Heaman, 1995; Palmer, 2001). Mothers of school-aged children with asthma frequently reported that the lack of cooperation and social support from the school system placed more burden on them (Palmer, 2001). Other studies of parents of children with high technology needs reported that the constancy of the demands was exhausting and contributed to a sense of caregiving burden (O'Brien, 2001; Ray & Ritchie, 1993; Teague et al., 1993). The burden of the physical care often overrode attention to child development and other family-related activities (O'Brien, 2001). Commonly reported personal caregiver burden issues included not getting enough sleep, fewer opportunities for socialization, or personal time (Eiser et al., 1993; Heaman, 1995; O'Brien, 2001; Sterling et al., 1996). To date, there have been no studies that explored what type of supports mothers of young children with type 1 diabetes used to help with the ongoing care required.

In summary, the empirical literature supports the complexity of managing a young child's illness in a way that maintains illness control while promoting optimal growth and development. Most previous research has focused broadly on illness management and how it is experienced. The intent of this study was to provide a detailed description of mothers' actual management behaviors and the meanings mothers attributed to them. Further exploration of these issues will help to design more precise nursing interventions that may assist mothers in the day-to-day management.

## RESEARCH DESIGN AND METHOD

Naturalistic inquiry guided the collection process, management, and analysis of the qualitative data findings (Lincoln & Guba, 1985). This method encourages use of multiple and unique descriptions of a phenomenon, including the experiences of mothers raising young children with diabetes. Purposive maximum variation sampling was used to include as much detailed and unique information as possible (Lincoln & Guba, 1985).

The study protocol was approved by the Yale School of Nursing Human Subjects Research Review Committee. A list of open-ended interview questions developed by the principal investigator guided each interview. The questions were based on current literature and then reviewed by 3 nurse researchers with expertise in chronic illness and qualitative research. Data collection and analysis were overlapping, and interviewing continued until

data saturation was reached ( $N = 28$  mothers) (Kvale, 1996).

To establish credibility, member checks with 6 of the mothers were also performed on a one-to-one basis. The central theme and associated categories, as well as subcategories, were reviewed. Discussion was open and informal, and the participants were encouraged to comment on the interpretation of data that emerged from the interviews. There was consistent agreement across all of the constructions, with only minor clarifications, which were incorporated into the findings.

A sample of English-speaking mothers of children under 4 years of age, diagnosed with type 1 diabetes for at least 3 months, were recruited after consulting with the staff in two regional diabetes clinics in the Northeast. All interviews were completed in the mothers' homes at a convenient time of day for them and lasted from 1.5 to 3 hours. Written informed consent forms were fully explained by the investigator, read, and signed by the participant before the interview. Each interview was conducted by the principal investigator and tape-recorded. Mothers were encouraged to freely share their thoughts. As a starting point, mothers were asked to "describe a typical day" in order to elicit a full picture of day-to-day life. Subsequent questions focused on gaining a detailed description of what mothers did to manage their children's illness and the meanings they ascribed to their management behaviors. Probes focused on issues such as how they learned their child's care, how they learned to recognize hypoglycemia, what kinds of physical signs and behaviors they looked for, how they managed their other daily responsibilities, the day-to-day concerns and stressors they experienced, and what kinds of internal and external resources they used. Field notes on what the researcher did, saw, and felt were written immediately after each interview.

Data management and analysis consisted of first having the tapes transcribed (professionally) and reviewing them as a whole in order to proofread for accuracy. All audiotapes were kept confidential (no identifying names were used in the written transcripts). Only the qualitative consultant, principal investigator, and transcriptionist had access to the tapes. In addition, field note descriptions were added to further describe the home visit (including any critical incidents that may have occurred) and to bracket the investigator's perceptions during the analysis process (Erlandson, Harris, Skipper, & Allen, 1993). The NUD\*IST software program (1997) was used to code, re-

trieve, and help organize the interview data. On the basis of a review of the transcripts, the investigator identified major categories. Coded data were reviewed again by the principal investigator and independently by the qualitative consultant, in order to describe the content of individual categories and identify overarching themes that characterized the mothers' experiences (Knafel & Webster, 1988).

## RESULTS

The mothers' mean age was 33 years (SD, 5.24 years), they had a mean of 15 years of education (SD, 2.5 years), and 86% ( $n = 24$ ) were married. Of the mothers, 89% ( $n = 25$ ) were white, which is reflective of the racial demographic distribution of type 1 diabetes in the Northeast (Malone, 1994). Over one half ( $n = 15$ ) of the mothers were not working outside of the home.

The children's mean age was 2.9 years (SD, 0.6 years); there were 18 male children and 10 female children. The male-to-female ratio represented by the study sample parallels the reported male preponderance in the age group diagnosed with diabetes at less than 5 years old (Jefferson, Smith, & Baum, 1985). The mean duration of illness was 1.25 years (SD, 0.7 years).

### Constant Vigilance

The central theme that emerged was "constant vigilance." Mothers described having to use hyper-vigilant caregiving behavior to accomplish the day-to-day management. This theme incorporated a cluster of management behaviors that included (a) ongoing monitoring of illness-related care, (b) identifying appropriate and safe resources that could meet the child's needs, and (c) "juggling" illness-related care with the developmental needs of the child. Constant vigilance was many times in

the foreground, and yet sometimes, as one mother described, "background music." The mothers in this study vividly described how their day-to-day concerns, illness-management tasks, and access or use of supportive resources were linked to their profound sense of continuous responsibility for providing precise quality care.

It is constant vigilance, thinking of, you know, constantly, where's your next meal coming from, do you have enough snacks, do you have all the insulin supplies with you that you need—sleeping with your eyes open. What's going on in the back of your head is, "OK, 2:30 I gave him 2 Humalog and 1/2 lente and I cut the Ultra 2 1/2, but you know, he wanted eggs and bacon for breakfast, he played outside, we're not going to be home in time for dinner, what time did he eat last, is the lente peaking right now . . .?" As you're saying he can go outside to play, this is not what I'm saying and this is not even on the forefront of what I'm thinking, but in the back that's what's going on. And as I'm doing things, I'm thinking about meals and carbohydrates and insulin levels and you know, growth spurts . . . .

Mothers described 3 aspects of constant vigilance: day-to-day concerns, day-to-day management, and supportive resources. A detailed diagram of categories and subcategories is shown in Figure 1.

Day-to-day concerns included an array of responsibilities that concerned mothers on a daily basis: daily monitoring tasks, hypoglycemia, long-term complications, and daycare issues. The day-to-day responsibility of the child's care was described as time-consuming because of the vigilant care required to manage the disease. It primarily involved keeping the child's glucose level in an acceptable range, while factoring in the child's activity, nutritional intake, and intermittent illnesses. There were several references to the day-

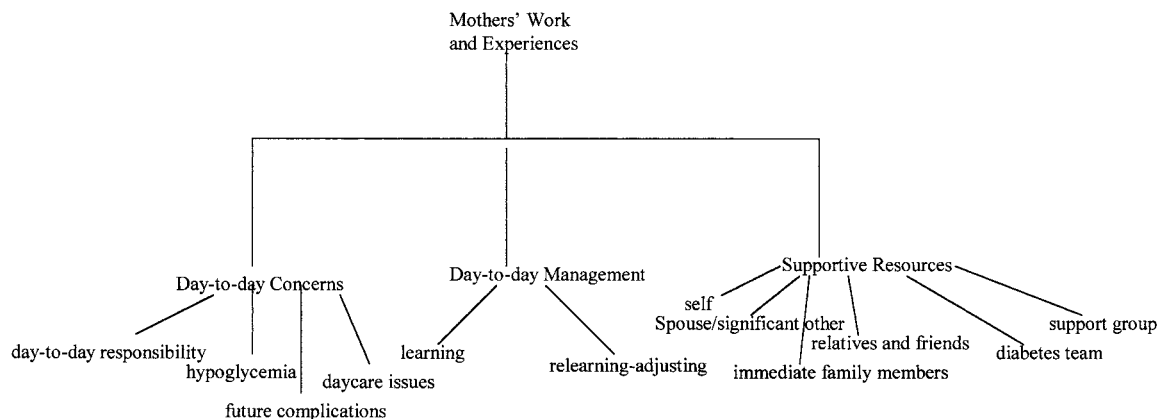


Figure 1. Categories and subcategories of mothers' work and experiences linked to constant vigilance.

to-day responsibility as being analogous to having a newborn again.

The mothers' concern about hypoglycemia and the potential for seizures was described consistently by all of the mothers as a tremendous fear. Nighttime and naptime were especially fearful times in this regard, especially in the early months after diagnosis. The fear and need to be constantly vigilant led to sleep deprivation for many of the parents. As one mother said,

I have this image of a ship going through a very narrow strait with very high sharp rocks on either side and you can hit something if you go . . . at nighttime you never really know what is going to hit.

Mothers also expressed concerns with future complications, but they felt that their present day-to-day management actions (constant vigilance) could greatly reduce long-term complications. In particular, mothers also reported having anxiety over the long-term effects of keeping their children in the lower glucose range for extended periods of time.

Concerns pertaining to daycare centers involved both the receptivity and abilities of the staff to appropriately care for a young child with diabetes. Being vigilant meant ongoing assessment of the competence of others caring for the child. Over half of the mothers reported that this was the reason for not having placed their children in a daycare center. Approximately one third of the children attended some type of daycare setting for short periods during the week. Although most mothers were satisfied with the care, several reported still worrying during the time the child was at school. A few mothers described daycare staff being either overconcerned with blood glucose testing or having management misperceptions, such as believing that providing orange juice for a child was an appropriate treatment for hyperglycemia. Thus the mothers' sense of responsibility was further magnified by their recognition that the resources intended to provide some respite were either limited or unable to meet the children's needs.

A few of the mothers reported that when they attempted to place their children in daycare, they were refused entry. Even with state daycare mandates and federal laws, such as the Americans with Disabilities Act in place, some daycare centers were refusing to accept young children with type 1 diabetes. The mothers were informed that the illness-related demands of these children would take time away from others in the daycare center.

Day-to-day management included not only

hands-on (direct) management skills, such as giving injections or recognizing behavioral cues that signify hypoglycemia versus normal behavioral responses, but also process-management (indirect) skills, such as problem-solving, interpreting, prioritizing, community resource advocacy, and continuity of care issues. For the purposes of this article, we will limit our findings and discussion to the hands-on care and problem-solving management skills. Mothers reported having to learn to master multiple illness-related caregiving skills, which occasionally needed modification because of changing developmental needs. Several mothers reported feeling angry and frustrated with the short hospital stay in which they were expected to quickly learn the necessary hands-on care and problem-solving skills to manage their child at home, with little recognition of the constant vigilance that was required and how to maintain it:

Yeah, they give you a bag of supplies and say 'OK, take her home, you'll be fine, right!'

The mothers described the overall day-to-day management as requiring consistency, persistence, flexibility, patience, creativity, and adaptability. One mother described how learning to use these skills gave her her life back:

You have to do it as a Boy Scout, you have to always 'Be Prepared.' So, there's a knapsack that I go through every Sunday and I make sure I have another glucometer in there, there's syringes, I have a double set of insulin for everything that I always keep in there, as well as a change of clothing and stuff for him, and enough snacks . . . enough to amount to, I guess, two meals. Every Sunday I go through and change and make sure everything has enough for the rest of the week and replace it as I go, and that had really given me back a lot of spontaneity.

The mothers described learning to interpret a variety of individualized behavioral cues that were indicators of either hypoglycemia or hyperglycemia. They described how the cues changed as the children moved through developmental milestones, requiring the relearning of a new set of cues and perhaps adjusting the illness management. Reading behavioral cues was also necessary for appropriately disciplining the child. Mothers reported having to learn to differentiate between symptoms of glucose changes and unacceptable behavior. Once that was determined, carrying out the appropriate intervention followed:

We were driving to the store and he was acting out so I pulled over the car and really looked at him and his behavior, he looked low, so I fed him and he calmed down.

Normally if he didn't have diabetes I would just have done a time out . . . You can't with diabetes.

All of the mothers reported that learning the care took time and that they were very fearful at first to go anywhere outside the home. Mothers described feeling isolated and incompetent and experiencing sleep deprivation, especially in the first 6 months after diagnosis. With time, mothers reported becoming very skilled in day-to-day illness management, including reading their children's behavioral cues. They described using rigid rules initially, but with time, they built up their confidence and began to relax. "I mean, it is a medical field . . . So that would be my first thing, it would be like . . . What are my first four words of advice? Time, time, time, and time. Eventually you begin to relax a bit."

Mothers also reported dips in confidence when severe hypoglycemia occurred. In fact, their level of confidence was shattered every time the child had a severe hypoglycemic episode. These episodes resulted in exacerbations of fear; mothers described the need to then rebuild their confidence. They also described being "super vigilant" after these events until they rebuilt an "I can handle this" attitude. For most, these dips in confidence were shortened the longer they managed the condition.

Supportive resources (both internal and external) were used to help mothers maintain the constant vigilance. Resources included self (i.e., inner strength), spouse/significant others, family unit members, relatives and friends, support groups, and the diabetes team. The majority of mothers described using inner strength to help them maintain the constant vigilance required, with only a small group of mothers feeling bitter, angry, and overwhelmed with the daily care. That group comprised the mothers with the fewest resources to help with their child's care (Sullivan-Bolyai et al., 2002).

Most of the mothers identified their spouse/significant other as an important resource, especially for emotional support. Spouses were also reported as providing occasional help with daily care, which gave some relief from the constant vigilance. All of the fathers in this study worked and were limited with regard to the hours they could spend helping with their children's care at home.

Immediate family members who were residing in the same home or nearby were also described as providing support. Mothers described their older children in many situations helping out in the care

of the child with diabetes. They routinely recognized and alerted the mother to subtle signs of beginning hypoglycemia. This type of help relieved the mothers, albeit for short periods of time, from the constant vigilance.

Mothers reported having limited access to babysitting, as well as concern about the abilities of others to manage the child's care, a concern that was directly linked to the constant vigilance of care. Only a few grandparents, parents' siblings, and sitters were reported to be available to help with babysitting. Fear was the explanation mothers gave as to why so few grandparents were willing to help out with the care. Relatives and friends were described in a number of the interviews as initially offering support, but many did not follow through on their offers. Friends who initially offered support were described as pulling away. One mother stated that everyone said they would help out and babysit, but once they were home, the offers were withdrawn. Several of the mothers reported not having time to spend with friends, which resulted from care responsibilities.

Support groups that were child age-specific were described as being especially helpful as a resource. For a variety of reasons, such as distance, access, or lack of babysitting resources, less than half of the mothers reported using parent support groups.

The diabetes team (which consisted of the physician, diabetes nursing specialists, nutritionist, and social worker), for the most part, was perceived as a helpful resource. Members of the team were always available for phone consultation and problem-solving assistance. Some of the mothers felt that the team members did not recognize the tremendous responsibility, ongoing monitoring required, and pressure that is put on them, with few breaks and little support. Several mothers reported that members of the diabetes team sometimes made them feel like they were not "doing good enough" or that they were "messing up."

### Burden of Constant Vigilance on Mothers' Physical and Emotional Health

Several mothers (especially those with limited resources) identified personal physical and emotional outcomes related to their constant vigilance. The ongoing responsibility and fear, as reported earlier, affected parental sleep, with reports of chronic sleep deprivation. Some mothers said the only way they could get any rest was to have the child sleep with them. Few mothers had shared this

information with the diabetes team because they feared they would be reprimanded.

The burden of care also resulted in some of the mothers experiencing personal health problems, such as depression, weight gain or loss, and migraines. Several mothers reported being hospitalized. They attributed these problems to the burden and responsibility of care with limited support or respite.

**DISCUSSION AND NURSING IMPLICATIONS**

Although the study included a small sample of mothers who were predominantly white, married, and well educated, limiting the transferability of the findings, the results nonetheless provide further insight into day-to-day illness management of young children with type 1 diabetes. The seminal work of Hatton et al. (1995) described the phases parents moved through after their young children were diagnosed with diabetes. This study further specifies how parents manage the hard work of constant vigilance that goes into parenting young children with diabetes, even with the advantages of being well educated and married and having health insurance coverage, as represented in this sample.

In this study “constant vigilance” was the primary behavior strategy mothers used for day-to-day management. The ongoing responsibility was compounded by the insecurity over whether one was providing adequate and vigilant care. Vigilant caregiving has also been described by parents of children diagnosed with asthma and children with high technology needs, such as ventilators and tracheostomies (O’Brien, 2001; Palmer, 2001). Palmer (2001) described families needing to be “ever-present” and having difficulty relinquishing or finding relief from their role, which is consistent with the findings in this study. Families with children who are technology-dependent use vigilance as a strategy to maintain stability in their daily lives (O’Brien, 2001). By careful monitoring of the child, they were able to avoid serious health-related problems that could put the child and family in crisis.

“Constant vigilance” was closely linked to the mothers’ fear of hypoglycemia. The mothers worried about whether they were being vigilant enough to recognize the signs of hypoglycemia and to prevent the long-term complications associated with type 1 diabetes. Hypoglycemia has also been previously reported as a concern for mothers of older children with diabetes (Banion et al., 1983; Betschart, 1988; Parker et al., 1994). It was clearly a major concern throughout the interviews and

could possibly be explained by the stricter glyce-mic control recommendations that followed the DCCT (ADA, 1999a). Our findings underscore the importance of the nurse working in partnership with the family to provide information, guidance, and reassurance pertaining to the management of hypoglycemia, especially in the early months after diagnosis (Table 1).

The loss of parental confidence and heightened vigilance associated with severe episodes of hypo-glycemia have not been described previously and deserve further exploration of how to better sup-port mothers’ efforts and emotional state at these junctures. Providing reassurance and validation that such reactions are normal is a critical role for nurses working with these families (Table 1).

Parental sleep deprivation, associated with fear of nighttime hypoglycemia, had not been previ-ously reported in empirical findings, nor had using a “family bed” to get more sleep. Perhaps mothers weighed the risks of co-sleeping and sleep deprivation. There is some evidence that co-sleeping in general is underreported in the United States (Rath & Okum, 1997). Recent findings also suggest that in cultures in which co-sleeping is common and accepted, there are fewer reports of sleep problems

**Table 1. Summary of Findings Associated With Constant Vigilance and Implications for Nursing Practice**

Finding	Implications for Nursing Practice
Concerns with hypoglycemia	<ul style="list-style-type: none"> <li>● Provide “what if” practice in clinic</li> <li>● Provide ongoing phone availability</li> <li>● Provide reassurance/validation of fears</li> <li>● Identify parent-to-parent support</li> <li>● Provide reassurance and validation</li> </ul>
Lapses in confidence in care	<ul style="list-style-type: none"> <li>● Provide confidence-building support</li> </ul>
Sleeping arrangements	<ul style="list-style-type: none"> <li>● Assess sleep issues</li> <li>● Provide information and guidance</li> <li>● Provide nonjudgmental clinic environment</li> </ul>
Daycare and school issues	<ul style="list-style-type: none"> <li>● Provide child rights information</li> <li>● Offer to participate in school meetings</li> <li>● Work with parents on school staff preparation</li> </ul>
Maternal health issues	<ul style="list-style-type: none"> <li>● Assess mother’s care of “self”</li> <li>● Encourage maintaining “self”</li> <li>● Identify personal respite sources</li> <li>● Assist family in developing “division of labor” plan</li> </ul>

(Latz, Wolf, & Lozoff, 1999). Nevertheless, the usual admonitions against such sleeping practices may require modification, given the particular demands of diabetes care in young children. Further investigation of these issues and how best to approach the topic with families is warranted (Table 1).

Our findings also suggest that, even when mothers have placed their children in daycare, they worry about the qualifications of the staff dealing with diabetes-related emergencies. The fact that over half of the mothers reported the same reasons for not having placed their children in daycare or nursery school makes this an important issue that should be addressed in the course of the care of these patients (Table 1). Upon diagnosis, parents should also receive a copy of the ADA general guidelines for the care of young children with type 1 diabetes in a daycare setting (ADA, 2001b). Teaching parents about their children's educational rights (i.e., Public Law 101-476: Individuals with Disabilities Education Act, parts B and C) should be a routine part of discharge planning. The centers were concerned primarily with checking the blood glucose levels, as well as the time involved in the monitoring. Similar reports have been cited in the literature regarding children with human immunodeficiency virus being denied entry to daycare (Anonymous, 1997). Even with federal laws in place to protect individuals with disabilities, parents may still need coaching on how to be a proactive advocate for their children (Table 1).

Most of the mothers described drawing on their inner strength and being positive in order to sustain the constant vigilance. These behavioral responses are similar to the intrapersonal factors associated with the empowerment process that mothers of young children with neurologic conditions described (Gibson, 1995). Making the best of the

situation and being positive contributed to maternal confidence and, for most of the mothers in our study, feelings of empowerment.

An especially important finding was mothers' reports of their own health problems that they attributed to the "constant vigilance" of care. These reports were not surprising and are also consistent with the existing empirical literature (Heaman, 1995; Patterson, Leonard, & Titus, 1992; Ray & Ritchie, 1993). The intensity of care took its toll on some of the mothers and, as the data suggest, especially on those with limited resources. As the existing literature points out, mothers who have adequate support manage more successfully and have fewer stressors that influence family life (Eiser et al., 1993; Sterling et al., 1996).

The lack of having appropriate child care or babysitting resources, and having fewer family/friends to help with the care, underlines the need for careful discharge planning and consistent follow-up, including helping mothers identify resources to decrease the burden of daily care. Our data support previously reported findings of the important role fathers play in providing mothers with emotional support (Nagy & Ungerer, 1990). Further assessment should explore ways to use fathers, other family members, and friends for more direct child care. Sharing with the mothers some of the day-to-day management topics that emerged from this study may benefit the function and preservation of the family unit (Table 1).

In conclusion, the findings of this study highlight the experiences and concerns of mothers with young children newly diagnosed with type 1 diabetes. Helping parents to be part of the health team is critical. Partnership with the family is key to providing parents with the support and recognition that they deserve, considering the care they are providing.

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