



Research Article

Volume 14 Issue 4 - April 2019  
DOI: 10.19080/JGWH.2019.14.555895

J Gynecol Women's Health

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# Daunting Challenges and Psychological Adaptation for Caregivers of Children with Type 1 Diabetes Mellitus



Shan-Mei Tang<sup>1</sup>, Tzu-Jou Wang<sup>2</sup> and Yuan-Ping Chang<sup>1\*</sup>

<sup>1</sup>Department of Nursing, Fooyin University, Taiwan

<sup>2</sup>Department of Pediatric, Chang-Gung Memory Hospital, Taiwan

Submission: March 15, 2019; Published: April 03, 2019

\*Corresponding author: Yuan-Ping Chang, Department of Nursing, Fooyin University, Taiwan

## Abstract

Previous studies had primarily focused on the Care for type 1 diabetes mellitus patients, rarely touched upon the struggles and psychological adaptation of the caregivers. The aim of this study was to define the life course for primary caregivers of children with type 1 diabetes mellitus. A qualitative descriptive research approach was adopted in the study. This study used semi-structured interviews to collect data and performed content analysis to analyse the data. The subjects (n=8) were enrolled using snowball sampling. The eight primary caregivers had been taking care of children with type 1 diabetes mellitus for more than five years. The analysis of the interviews acknowledged four themes in the life courses of primary caregivers, including experiencing shock resulting from the initial diagnosis, feeling tormented and lost, facing constant family conflicts, and meeting a bosom friend and finding support. As expected, the article identifies the care experience as a reference for healthcare professionals taking care of caregivers of children with type 1 diabetes mellitus. The findings showed that the caregivers of children with type 1 diabetes mellitus were lonely and faced difficulties. A supportive atmosphere can initialise the courage needed to break through the predicaments of the adaptation process.

**Keywords:** Type 1 diabetes (T1DM); Child; Caregiver; Psychological adaptation

## Introduction

Type 1 diabetes (T1DM) is a common chronic disease in children. Children are highly dependent on their families and are sensitive to the impacts of rapid physical and psychological development [1,2]. Once T1DM is diagnosed and it is confirmed that there is no cure for lifetime comorbidity of T1DM, there is a notable impact on parents or primary caregivers (hereafter replaced by "caregivers") [3]. Caregivers worry that the sudden onset of complications or diabetic ketoacidosis/hypoglycaemia will endanger the health, growth, future progress and education of the children [4,5]. Caregivers play an important role in the growth of children, and their feelings and negative perspectives affect the adolescents' control over their diabetes [6, 7].

When children enter school, caregivers worry about their adaptation to school and their control over their glycaemic levels. Past surveys have discovered that school personnel are unable to identify hypoglycaemia and do not have diabetes training [7,8]. Some schools even indicate that they are unable to accept children with T1DM, advise transferring schools due to difficulties in care, or request that caregivers assist in care at school [9,10]. The school environment is not friendly

towards diabetic students. However, foreign and domestic studies investigating the life course of children or adolescents with T1DM have seldom looked at the feelings of caregivers. Therefore, this study aims to explore the psychological process of caregivers who take care of children with T1DM.

## Materials and Methods

### Research design and participants

This study performed in-depth qualitative research interviews that lasted approximately 45-90 minutes to collect data. This study used snowball sampling to enrol participants at the outpatient clinic of a hospital. The inclusion criteria were as follows: caregivers taking care of children with T1DM in a family for at least five years and able to communicate in Chinese or Taiwanese. This study enrolled a total of 8 caregivers in a family taking care of children with T1DM, including 4 mothers, 3 fathers (1 of them is a single father), and 1 uncle (his older brother had died in a car accident, his sister-in-law had remarried, and his 2 nieces with T1DM lived with him and their grandparents). This study used semi-structured interviews to collect data.

In principle, the interview locations were places without any disturbance.

### Ethical consideration

This study was reviewed and approved by the Research Ethics Committee (NO: 100329-7). After verbally explaining this study, the author obtained the written consent of the participants to record or summarize the interviews. The interview contents were recorded via actual communications.

### Survey questions and survey analysis

The same researcher was responsible for collecting the data and interviewing the participants. This study used semi-structured interviews to collect data. The interview questions included information on the feeling of the child after the initial diagnosis, the problems encountered during the process and how they were handled, and any impressive changes or feelings over the course of the process. The data reached saturation after data from the 7th participant were collected. No new data appeared in the 8th participant, so the enrolment was terminated. This study performed content analysis on the collected data. Upon completion of the transcription, three nursing masters/doctors who are diabetic educators collaboratively found and decoded meanings that were coded from meaningful situational contexts and summarized the themes to understand the overall contextual background of the phenomenon and its important meanings.

### Result

After analysis of the interview data, the research results displayed the life course for primary caregivers of children with T1DM. The four themes included are listed below (Figure 1).

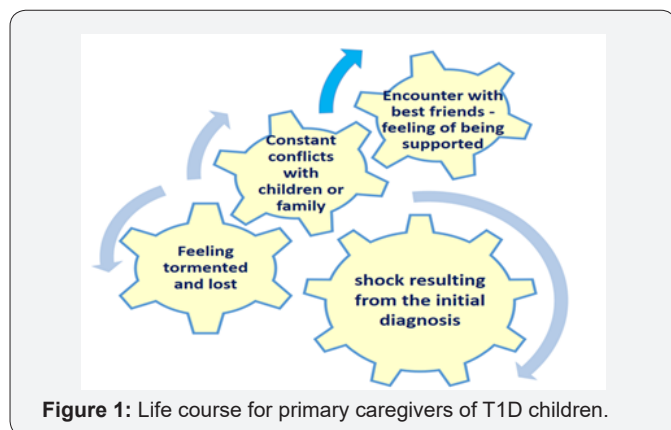


Figure 1: Life course for primary caregivers of T1D children.

### Shock resulting from the initial diagnosis

In the interviews about the psychological process after the initial diagnosis of the children, the participants' chief reactions to the sudden event—their children being diagnosed with T1DM—were emotional feelings: "Shocked! Terrified...I have no idea what complications or problems may occur in the future"; "A bolt out of the blue...How could this happen?"; "...I have no idea what to say...When the doctor explained the disease condition, we still stood there and had no idea what to say and what to do"; "It was like the end of the world..."; "I felt panicked and terrified! I worry

about my children's future career or complications. After all, we cannot live with them their entire life... Besides, I have no idea what T1DM is and how to care for it. Can the children take care of themselves in the future?"

### Feeling tormented and lost

After children received a series of treatments in the hospital, the participants faced the issue of how to take care of the children at home. After consulting with medical and nursing personnel or searching for information online, the participants gradually began to understand what T1DM is. However, they started to feel pity and distress for their children. The chief complaints were as follows: "T1DM is like an untimed bomb, which threatens parents at any time"; "It hurts! I have no idea what to say or whom to say it to"; "Although folk remedies or recipes are ridiculous...I would still try them"; "I am afraid that other people may know about it...They might say that it is karma..."; "I'd like to commit suicide with my child..."; "My mother-in-law blamed me for my family genes...However, no one in my family suffers from diabetes"; "I worry about my child"; "Diabetes can cause many complications, which is terrifying."

When the participants were asked about the comparisons between the past and current care for children and the current status, they answered in the following way: "I had no idea how to console him (the child) when I stood by him...I started to scold him when I became impatient"; "In the beginning, I scolded my child...I had no idea what to do, either"; "I was even more nervous than my child, and my child felt strange"; "We were nervous. When we became more nervous, we started to speak loudly"; "When my child cried, I also cried." In addition, the participants also indicated that their moods would change with the glycaemic level of children.

For example, "My mood is affected 24/7...It changes with the glycaemic level"; "My mood changes with the glycaemic level of my child"; "...I feel very sad. I want to vent my anger, but I have no idea how to vent it."

In the interviews about the problems or feelings experienced when control over the children's glycaemic level does not go as expected, they said, "I will try my best to control my mood to prevent my child from being affected by my emotional changes." The chief complaints were: "The glycaemic level of my child was as high as 200. However, I could not express my anger too obviously...Especially after my child eats high-sugar food and the glycaemic level increases to 300...I still have to suppress my emotions. It hurts!" Particularly, in reaction to a child having once said, "Why am I the one to receive injections? Why aren't the adults?" the caregiver said "My mood at the time was, 'It hurts!... Whom should I talk to?'...I'd like to commit suicide with my child."

Some participants even indicated that they were afraid of taking their children outdoors. They said, "Our family did not travel together for many years...It took us a very long time to adapt to it"; "I felt worried about my child participating in a

graduation trip or outing"; "There are too many variables if I take my child outdoors, and so I can't allow my child to go outdoors for too long, let alone to participate in an overnight trip...I worry that my child cannot receive medical treatment in case of hyperglycaemia. I am also afraid that the doctor is not aware of my child's disease condition like the original doctor is."

### Facing Constant family conflicts

When children's glycaemic control is poor or the changes in parent-child interactions and lifestyle do not reach a balance, there are constant conflicts. The participants said, "I will cry with my child"; "After scolding my child for poor glycaemic control, my child cried and I also cried"; "He [the child] was already afraid of high glycaemic levels." The participants said, "My own negative attitude actually hurts my child as well"; "In the beginning, I scolded my child..."; "In the beginning, I would get angry when I saw a high glycaemic level"; "My negative attitude [scolding] and tension caused by impatience made my child [feel strange]"; "When I lost my temper, my child was even more mad than I was"; "He [the child] would tell me that he intended to die..."

The participants indicated that there were even more conflicts, especially when the children reached puberty and their control was even more unstable. For example, "At puberty, her glycaemic control became unstable"; "My child lied to me...he tampered with the glycaemic level..." "Originally, we checked the box of "Disagree" with the class trip on the contact sheet. She changed it to [Agree]...Had the teacher not contacted us, we wouldn't have known this." The participants originally wished that their children could obtain more assistance and attention from teachers and peers at school. However, their children did not want this, which led to them complaining. "After my child was discharged from the hospital and returned to school, the teacher announced in class that he [the child with T1DM] suffers from diabetes. Although the teacher did it with good intention, it turned out differently. My child cried and said, 'Everyone looked at me...It seemed like I was a monster'; "My child was treated differently."

### Meeting a bosom friend and finding support

In the interviews about the substantial feelings throughout the process, the participants indicated: "It's a difficult and bumpy journey...Other patients introduced IDDM (Insulin Dependent Diabetes Mellitus) patient groups in southern Taiwan to us. At the time, it felt like catching a floating piece of wood in the ocean. Although medical and nursing personnel showed care, I could not feel it"; "I felt that he [the other patient/caregiver] understood me"; "I gradually adapted to...I persuaded myself that the number [the glycaemic level] ultimately is a reference value"; "I would share with others the change in my concepts... After my attitude changed slowly, I started to accept the facts"; "Through mutual sharing and support from other patients, I started to learn to sympathize with my child and set myself free...My mood was more pacified, and I now know where to seek assistance or spiritual consolation." The participants described

the assistance provided by patient groups: "Participating in patient groups enabled my child with T1DM to not feel alone"; "Other caregivers/patients understand me"; "I feel support through mutual understanding and sharing...a sense of warmth."

### Discussion

The research results showed that upon initial diagnosis of children with T1DM, the 8 caregivers all felt were heavily impacted by negative feelings and could not get rid of negative emotions and their impact for a long time [11]. They even continued to cry and talk about the entangled psychological process during the interviews. Seven caregivers suggested that despite the medical teams' assistance and professional knowledge, they seldom felt that they were understood. According to the data, they bore the burden of taking care of their children. Therefore, medical and nursing personnel should pay more attention to providing psychological support for caregivers. Mutual sharing among patients/caregivers is an important source that helps them eliminate negative attitudes and face problems. Support groups enable caregivers to discover that they are not alone [12]. Two caregivers even proactively go to the hospital to visit families who have children who are newly diagnosed with T1DM. They also regularly hold activities with the Catholic Sanipax Socio-Medical Service & Education Foundation or with T1DM patient groups. They feel that the emotional exchanges and the activity of sharing experiences not only helps themselves heal but also helps other people find the right path. They now take a much more proactive path towards helping others.

In the course of making children's glycaemic levels more stable, most of the caregivers cause conflicts with family or children. Excessive intervention reduces children's self-care responsibility and leads to poor glycaemic control [13]. However, too little participation by parents leads to unstable glycaemic control [14]. Nevertheless, under excessive glycaemic monitoring, children experience emotional distress and reduced satisfaction with school [7,15]. However, children with T1DM do not intend to worry caregivers [15-17], which is consistent with the research findings of this study concerning the entangled and complicated psychological process of caregivers. Caregivers expressed the wish that schools could provide more assistance and care, and therefore, establishing a care model suitable for schools and families is advised. During the care process, the interventions, interactions with children, and the responsibility for children must be shared by caregivers and properly controlled. Therefore, the research results can help spur more empathy for understanding caregivers' feelings. Hopefully, caregivers can better stabilize the care they give to the children, improve care quality, and create a win-win situation between parents and children with a full support network [18]. However, it is also necessary for teachers to be attentive and to not treat children with T1DM differently from other students. Children with T1DM wish to interact with their peers in a normal way and be treated equally so as to live a normal life without being stigmatized [19-21].

### Implications of the study

This study provides suggestion that the challenges and psychological adaptation of the primary caregivers for T1DM patients were imperative. The negative impacts on caregivers could be meaningfully mitigated through the experience-sharing and interactions among the caregiver support groups.

### Conclusion

This study helps the understanding of the many impacts and hardships encountered by caregivers during their care for children with T1DM. The author benefited a lot from contact with the patient groups and the sharing of their experiences, which enabled the author to obtain information on spiritual consolation and valuable practical experiences of care.

### Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

### Acknowledgement

The authors would like to express our appreciation to all participants in this study.

### References

- Chatterjee S, Riewpaiboon A, Piyathakitt K, Riewpaiboon W, Boupajit K, et al. (2011) Cost of diabetes and its complications in Thailand: a complete picture of economic burden. *Health Soc Care Community* 19(3): 289-298.
- Williams C, Sharpe L, Mullan B (2014) Developmental challenges of adolescents with type 1 diabetes: The role of eating attitudes, family support and fear of negative evaluation. *Psychol Health Med* 19(3): 324-334.
- AlBuhairan F, Nasim M, Al Otaibi A, Shaheen NA, Al Jaser S, et al. (2016) Health related quality of life and family impact of type 1 diabetes among adolescents in Saudi Arabia. *Diabetes Res Clin Pract* 114: 173-179.
- Chae M, Taylor BJ, Lawrence J, Healey D, Reith DM, et al. (2016) Family CHAOS is associated with glycaemic control in children and adolescents with type 1 diabetes mellitus. *Acta Diabetol* 53(1): 49-55.
- Eilander MMA, Snoek FJ, Rotteveel J, Aanstoot HJ, Bakker-van Waarde WM, et al. (2017) Parental diabetes behaviors and distress are related to glycemic control in youth with type 1 diabetes: Longitudinal data from the DINO study. *J Diabetes Res* p. 7.
- Butler JM, Berg CA, King P, Gelfand D, Fortenberry K, et al. (2009) Parental negative affect and adolescent efficacy for diabetes management. *J Fam Psychol* 23(4): 611-614.
- Jesić MD, Milenković T, Mitrović K, Todorović S, Zdravković V, et al. (2016) Problems in diabetes management in school setting in children and adolescents with type 1 diabetes in Serbia. *Vojnosanit Pregl* 73(3): 273-276.
- Särnblad S, Berg L, Detlofsson I, Jönsson A, Forsander G, et al. (2014) Diabetes management in Swedish schools: A national survey of attitudes of parents, children, and diabetes teams. *Pediatr Diabetes*, 15(8): 550-556.
- Amillategui B, Mora E, Calle JR, Giralt P (2009) Special needs of children with type 1 diabetes at primary school: Perceptions from parents, children, and teachers. *Pediatric Diabetes* 10(1): 67-73.
- Gaston AM, Cottrell DJ, Fullen T (2012) An examination of how adolescent-caregiver dyad illness representations relate to adolescents' reported diabetes self-management. *Child Care Health Dev* 38(4): 513-519.
- Zamzam S, Anoosheh M, Ahmadi F (2013) Barriers to diabetes control from Syrian women's perspectives. *Jpn J Nurs Sci* 10(1): 121-129.
- Fritz HA (2017) Challenges to developing diabetes self-management skills in a low-income sample in North Carolina, USA. *Health Soc Care Community* 25(1): 26-34.
- Chien SC, Larson E, Nakamura N, Lin SJ (2007) Self-care problems of adolescents with type 1 diabetes in southern Taiwan. *J Pediatr Nurs* 22(5): 404-409.
- Hilliard ME, Eshtehardi SS, Minard CG, Saber R, Thompson D, et al. (2018) Strengths-based behavioral Intervention for parents of adolescents with type 1 diabetes using an mHealth App (Type 1 Doing Well): Protocol for a pilot randomized controlled trial. *JMIR Res Protoc* 7(3): e77.
- Madsen SD, Roisman GI, Collins WA (2002) The intersection of adolescent development and intensive intervention: Age-related psychosocial correlates of treatment regimens in the diabetes control and complication trial. *J Pediatr Psychol* 27(5): 451-459.
- Hanna KM, Weaver MT, Slaven JE, Fortenberry JD, DiMeglio LA, et al. (2014) Diabetes-related quality of life and the demands and burdens of diabetes care among emerging adults with type 1 diabetes in the year after high school graduation. *Res Nurs Health* 37(5): 399-408.
- Wang YL, Brown SA, Horner SD (2010) School-based lived experiences of adolescents with type 1 diabetes: A preliminary study. *J Nurs Res* 18(4): 258-265.
- Rossiter C, Fowler C, Hesson A, Kruske S, Homer CS, Kemp L, Schmied V (2018) Australian parents' experiences with universal child and family health services. *Collegian*.
- Brazeau AS, Nakhla M, Wright M, Henderson M, Panagiotopoulos C, et al. (2018) Stigma and its association with glycemic control and hypoglycemia in adolescents and young adults with type 1 diabetes: Cross-sectional study. *J Med Internet Res* 20(4): e151.
- Huang LC (2004) Sharing the journey: The story of a child with insulin-dependent diabetes. (Master degree), Nanhua University, Chiayi.
- Lin HP, Mu PF, Lee YJ (2008) Mothers' experience supporting life adjustment in children with T1DM. *West J Nurs Res* 30(1): 96-110.



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DOI: [10.19080/JGWH.2019.14.555895](https://doi.org/10.19080/JGWH.2019.14.555895)

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