

Children Behavior with Type 1 Diabetes: A Mini Review

Lopamudra Mishra¹, Lizasmita Patel¹, Neha Bhatia¹

¹Rourkela Senior Nursing College, Sambalpur University, Odisha, India.

Corresponding Author: bhatianeha757@gmail.com

Abstract: To synthesise the qualitative evidence on parents' experiences of caring for a child aged ≤ 8 years with type 1 diabetes to identify: the challenges they encounter; their views about support received; ways in which support could be improved; and, directions for future research. The synthesis resulted in the generation of two overarching themes. Monopolisation of life describes the all-encompassing impact diabetes could have on parents due to the constant worry they experienced and the perceived need for vigilance. It describes how parents' caring responsibilities could affect their wellbeing, relationships and finances, and how a lack of trusted sources of childcare and a desire to enable a 'normal' childhood constrained personal choices and activities. However, use of diabetes technologies could lessen some of these burdens. Experiences of professional and informal support describes how encounters with healthcare professionals, while generally perceived as helpful, could lead to frustration and anxiety, and how connecting with other parents caring for a child with type 1 diabetes provided valued emotional and practical support.

Key Words: —*Type 1 diabetes, parents, child, diagnosis.*

I. INTRODUCTION

Type 1 diabetes is one of the most common chronic childhood conditions and its incidence is rising worldwide including among pre-school aged children. This condition is now mostly managed using flexible intensive insulin regimens, which involve multiple daily tasks (e.g., regular blood glucose monitoring, carbohydrate counting, calculating and administering insulin) and may present different issues and challenges to conventional regimens based on fixed schedules and insulin doses [1]. For young children (those aged ≤ 8 years), however, most of these tasks are too complex to undertake independently; hence, parents/caregivers typically take on and/or oversee these responsibilities. The physiological, cognitive, behavioural and socio-emotional issues at this developmental stage make diabetes management challenging and clinically recommended blood glucose targets difficult to achieve. Hence, caring for a young child with diabetes can be overwhelming and stressful for parents, and can affect wider family life [2]. To date, no reviews have focused on parents' everyday experiences of caring for a young child with type 1 diabetes.

This review aims to address this gap. By identifying, examining and synthesising the qualitative evidence on parents' experiences of caring for a young child with type 1 diabetes, we sought to describe the published evidence base, identify the challenges parents encounter when managing their child's diabetes, explore their views about support received from health professionals and other sources, identify ways in which support could be improved and identify gaps in the evidence base and directions for future research [3].

II. METHODOLOGY

Thomas and Harden's thematic synthesis approach were followed, which is well suited to reviews focused on individuals' perspectives and experiences. This approach involves a systematic search of relevant literature, quality appraisal of the included studies. We identified papers for inclusion from a systematic search of electronic databases (Medline, EMBASE, CINA HL, PsycINFO and Web of Science) [4]. Working with a medical library science professional, we developed a search strategy that drew on existing literature and a combination of Medical Subject Heading (MeSH) terms and keywords relating to our target condition, population and methodology. Our searches were also informed by the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) approach to identifying qualitative literature, and search terms were tailored to suit each database. We screened the reference lists of included studies and relevant reviews identified by the

Manuscript revised August 14, 2022; accepted August 15, 2022. Date of publication August 16, 2022.

This paper available online at www.ijprse.com

ISSN (Online): 2582-7898; SJIF: 5.59

search to identify further papers for inclusion. Our choice of age cut-off at ≤ 8 years was informed by the literature highlighting the high level of parental responsibility for diabetes management tasks in this younger age group [5,6]. Subsequently, increasing maturity and independence sees children assume progressively more responsibility for their own diabetes care; this transition changes parents' role in their child's diabetes management, and thus their experiences, and was outside the scope of this review.

III. RESULTS

The 14 included papers reported the views and experiences of 274 parents in seven countries: Canada, United States, United Kingdom, Sweden, Norway, Iran and Palestine [7]. Four papers reported exclusively on the experiences of parents of children aged ≤ 8 years. The provision of information about study participants' sociodemographic characteristics varied greatly. Across all studies, the majority of parents were reported as being: married or co-habiting, qualified to higher education level and in employment. All studies employed interviews; one additionally used online focus group discussions [8-10]. Most studies considered parents' holistic experiences of caring for a young child with type 1 diabetes, with some focusing specifically on the experiences of mothers. Two papers described parents' everyday experiences of managing their child's condition using insulin pumps.

3.1 Synthesis findings

Two overarching analytical themes resulting from our synthesis, Monopolisation of life and Experiences of professional and informal support, with each theme comprising several subthemes. Primary authors' recommendations for how parent support could be improved in respect of the issues identified [11,12]. Across the studies, parents noted how the complexities and unpredictability of type 1 diabetes made it a very tiring disease to manage. Hypoglycaemia, in particular was an all-pervasive concern borne from several considerations [13]. The child being too young to recognise and report low blood glucose, some children's poor hypoglycaemia awareness and parents' awareness of the potential deadly consequences of hypoglycaemic events. Parents' concerns were greatest during the night, when they worried that severe hypoglycaemia might go undetected and threaten their child's safety [14,15]. To alleviate their fears, they described testing blood glucose regularly throughout the night, leading to exhaustion and chronic sleep deprivation. Some parents recognised that their

actions could be borne from irrational fears, but preferred being hyper-vigilant to having potential future regrets.

3.2 Relationships impact

Several studies highlighted how caregiving responsibilities not only monopolised parents' own lives, but also affected their relationship with the child. Managing their child's condition was described as requiring an atypical level of caregiving input, with some mothers likening their experience to caring for a new-born [16]. Mothers and fathers also described how their relationships with one another had changed as a result of having to 'live with constant attention directed at the diabetes condition. This could sometimes lead to conflict between parents, but also encouraged more in-depth communication about how best to manage their child's diabetes [17,18]. Similarly, many parents felt unable to entrust the care of their child to relatives and others in the community, as they perceived them as largely ignorant about diabetes and insufficiently vigilant about its management. Finally, several studies described how parents were determined not to let diabetes dominate their child. so that the child could 'have her innocence, to go out and play and feel like a normal child without feeling there is something different with her [19]. To facilitate this 'normality', parents adopted strategies that required even more of their time and effort, such as becoming actively involved in school and social activities to allow the child to participate while ensuring a watchful eye on their glucose needs.

IV. DISCUSSION

This review is the first to synthesise and describe the findings from qualitative studies, which report parents' everyday experiences of caring for a child aged ≤ 8 years with type 1 diabetes [20,21]. It highlights the all-encompassing, relentless and enduring nature of parents' care experiences and how their lives are dominated by constant worry. The need to be vigilant and a desire to enable their child to have a 'normal' childhood. Moreover, the synthesis illustrates how caregiving responsibilities could be detrimental to parents' own physical, psychological and emotional well-being, relationships, personal choices and everyday activities [22]. Parents' encounters with health care professionals, while generally perceived as helpful, could add to their anxieties and frustrations, as could lack of access to trusted sources of childcare and informal support [23]. Some parents, particularly mothers, described how they were forced to make decisions about employment based on their child's diabetes

care needs and associated expenses. Furthermore, even parents who self-identified as middle-class and were in possession of medical insurance reported experiencing diabetes-related financial strains due to at least some treatment supplies needing to be paid for through personal means [24]. Resonating with these findings, a survey conducted with parents of young children with type 1 diabetes found that having a child with diabetes influenced the employment decisions of 60% of parents (89.5% of them mothers), with nearly one quarter reducing or quitting work and others maintaining employment for financial reasons [25]. Research has also shown that caring for a child with type 1 diabetes was significantly more detrimental to their work and finances compared with parents of children with other or no special healthcare needs.

V. CONCLUSION

The current literature consistently describes caring for a young child with type 1 diabetes as an all-encompassing and relentless undertaking, which can have a detrimental impact on parents' own well-being, relationships, personal choices and everyday activities [26,11]. However, significant limitations and gaps in this literature mean that parents' experiences may in fact be more diverse than is currently recognised, which could have implications for the support they require from healthcare professionals [12]. In particular, we recommend that future research should explore how sociodemographic factors and use of newer diabetes technologies influence parents' diabetes management practices and experiences of caring for a young child with type 1 diabetes.

REFERENCES

- [1]. Lawrence JM, Divers J, Isom S, Saydah S, Imperatore G, Pihoker C, Marcovina SM, Mayer-Davis EJ, Hamman RF, Dolan L, Dabelea D, Pettitt DJ, Liese AD. Trends in prevalence of type 1 and type 2 diabetes in children and adolescents in the US, 2001–2017. *JAMA*. 2021;326(8):717–27.
- [2]. Streisand R, Monaghan M. Young children with type 1 diabetes: challenges, research, and future directions. *Curr Diab Rep*. 2014;14(9):520.
- [3]. American Diabetes Association. 13 children and adolescents: standards of medical care in diabetes—2021. *Diabetes Care*. 2021;44(Suppl 1):S180–99.
- [4]. Miller VA, Xiao R, Slick N, Feudtner C, Willi SM. Youth involvement in the decision to start CGM predicts subsequent CGM use. *Diabetes Care*. 2020;43(10):2355–61.

- [5]. Noser AE, Dai H, Marker AM, Raymond JK, Majidi S, Clements MA, Stanek KR, Patton SR. Parental depression and diabetes-specific distress after the onset of type 1 diabetes in children. *Health Psychol*. 2019;38(2):103–12.
- [6]. Iversen AS, Graue M, Haugstvedt A, Raheim M. Being mothers and fathers of a child with type 1 diabetes aged 1 to 7 years: a phenomenological study of parents' experiences. *Int J Qual Stud Health Well-being*. 2018;13(1):1487758.
- [7]. Nieuwesteeg A, Hartman E, Emons W, van Bakel H, Aanstoet HJ, van Mil E, Pouwer F. Paediatric parenting stress in fathers and mothers of young children with type 1 diabetes: a longitudinal study. *Diabet Med*. 2017;34(6):821–7.
- [8]. Wang CH, Tully C, Monaghan M, Hilliard ME, Streisand R. Source-specific social support and psychosocial stress among mothers and fathers during initial diagnosis of type 1 diabetes in young children. *Fam Syst Health*. 2021;39(2):358–62.
- [9]. Mauras N, Mazaika P, Buckingham B, Weinzimer S, White NH, Tsalikian E, Hershey T, Cato A, Cheng P, Kollman C, Beck RW, Ruedy K, Aye T, Fox L, Arbelaez AM, Wilson D, Tansey M, Tamborlane W, Peng D, Marzelli M, Winer KK, Reiss AL. Longitudinal assessment of neuroanatomical and cognitive differences in young children with type 1 diabetes: association with hyperglycemia. *Diabetes*. 2015;64(5):1770–9.
- [10]. Cato MA, Mauras N, Mazaika P, Kollman C, Cheng P, Aye T, Ambrosino J, Beck RW, Ruedy KJ, Reiss AL, Tansey M, White NH, Hershey T. Longitudinal evaluation of cognitive functioning in young children with type 1 diabetes over 18 months. *J Int Neuropsychol Soc*. 2016;22(3):293–302.
- [11]. Praveen PA, Hockett CW, Ong TC, Amutha A, Isom SP, Jensen ET, Mohan V, Dabelea DA, D'Agostino RB Jr, Hamman RF, Mayer-Davis EJ, Lawrence JM, Dolan LM, Kahn MG, Madhu SV, Tandon N. Diabetic ketoacidosis at diagnosis among youth with type 1 and type 2 diabetes: results from SEARCH (United States) and YDR (India) registries. *Pediatr Diabetes*. 2021;22(1):40–6.
- [12]. Dabelea D, Rewers A, Stafford JM, Standiford DA, Lawrence JM, Saydah S, Imperatore G, D'Agostino RB Jr, Mayer-Davis EJ, Pihoker C. Trends in the prevalence of ketoacidosis at diabetes diagnosis: the SEARCH for diabetes in youth study. *Pediatrics*. 2014;133(4):e938–45.
- [13]. Duca LM, Reboussin BA, Pihoker C, Imperatore G, Saydah S, Mayer-Davis E, Rewers A, Dabelea D. Diabetic ketoacidosis at diagnosis of type 1 diabetes and glycemic control over time: The SEARCH for diabetes in youth study. *Pediatr Diabetes*. 2019;20(2):172–9.
- [14]. Aye T, Mazaika PK, Mauras N, Marzelli MJ, Shen H, Hershey T, Cato A, Weinzimer SA, White NH, Tsalikian E, Jo B, Reiss AL, Diabetes Research in Children Network Study Group. Impact of early diabetic ketoacidosis on the developing brain. *Diabetes Care*. 2019;42(3):443–9.
- [15]. Tansey M, Beck R, Ruedy K, Tamborlane W, Cheng P, Kollman C, Fox L, Weinzimer S, Mauras N, White NH, Tsalikian E, Diabetes research in children network.

- Persistently high glucose levels in young children with type 1 diabetes. *Pediatr Diabetes*. 2016;17(2):93–100.
- [16]. Van Name MA, Hilliard ME, Boyle CT, Miller KM, DeSalvo DJ, Anderson BJ, Lafel LM, Woerner SE, DiMeglio LA, Tamborlane WV. Night time is the worst time: parental fear of hypoglycemia in young children with type 1 diabetes. *Pediatr diabetes*. 2018;19(1):114–20.
- [17]. Ly TT, Maahs DM, Rewers A, Dunger D, Oduwole A, Jones TW. ISPAD Clinical Practice Consensus Guidelines 2014. Assessment and management of hypoglycemia in children and adolescents with diabetes. *Pediatr Diabetes*. 2014;15(Suppl 20):180–92.
- [18]. Chiang JL, Kirkman MS, Lafel LMB, Peters AL. Type 1 diabetes through the life span: a position statement of the American Diabetes Association. *Diabetes Care*. 2014;37(7):2034–54.
- [19]. DiMeglio LA, Acerini CL, Codner E, Craig ME, Hofer SE, Pillay K, Maahs DM. ISPAD clinical practice consensus guidelines 2018: glycemic control targets and glucose monitoring for children, adolescents, and young adults with diabetes. *Pediatr Diabetes*. 2018;19(Suppl 27):105–14.
- [20]. Bantle JP, Wylie-Rosett J, Albright AL, Apovian CM, Clark NG, Franz MJ, Hoogwerf BJ, Lichtenstein AH, Mayer-Davis E, Mooradian AD, Wheeler ML. Nutrition recommendations and interventions for diabetes: a position statement of the American Diabetes Association. *Diabetes Care*. 2008;31(Suppl 1): S61-78.
- [21]. Patton SR, Clements MA, George K, Goggin K. “I don’t want them to feel different”: a mixed methods study of parents’ beliefs and dietary management strategies for their young children with type 1 diabetes mellitus. *J Acad Nutr Diet*. 2016;116(2):272–82.
- [22]. Monzon AD, Smith LB, Powers SW, Dolan LM, Patton SR. The association between glycemic variability and macronutrients in young children with t1d. *J Pediatr Psychol*. 2020;45(7):749–58.
- [23]. Tully CB, Toaf M, Herbert L, DiPietro L, Henderson C, Cogen F, Streisand R. Acceptability and feasibility of examining physical activity in young children with type 1 diabetes. *J Pediatric Health Care*. 2018;32(3):231–5.
- [24]. Adolfsson P, Riddell MC, Taplin CE, Davis EA, Fournier PA, Annan F, Scaramuzza AE, Hasnani D, Hofer SE. ISPAD clinical practice consensus guidelines 2018: exercise in children and adolescents with diabetes. *Pediatr Diabetes*. 2018;19(Suppl 27):205–26.
- [25]. 2018 Physical Activity Guidelines Advisory Committee. Part F. Chapter 7. Youth. In: 2018 Physical Activity Guidelines Advisory Committee Scientific Report to the Secretary of Health and Human Services. 2018.
- [26]. Kimbell B, Lawton J, Boughton C, Hovorka R, Rankin D. Parents’ experiences of caring for a young child with type 1 diabetes: a systematic review and synthesis of qualitative evidence. *BMC Pediatr*. 2021;21(1):160.