ORCID IDs
Андрій Черкас:
   https://orcid.org/0000-0002-6652-6983
Велека Аллен:
   https://orcid.org/0000-0002-3479-0384
Стефані Баскл:
   https://orcid.org/0000-0002-7480-1439
Еллен Касіредді:
   https://orcid.org/0000-0002-2149-3671
Рен Чен Мін:
   https://orcid.org/0000-0002-2623-322X
Дівія Пушкарна:
   https://orcid.org/0000-0002-6680-4074
Мір-Масуд Пурахмат:
   https://orcid.org/0000-0001-7975-8823
Аймерік Маю:
   https://orcid.org/0000-0003-1846-2783

Людський тягар у неформальних опікунів дітей та молодих дорослих, у яких нещодавно діагностовано цукровий діабет першого типу: систематичний огляд літератури

Андрій Черкас[1]*, Велека Аллен[2], Стефані Баскл[3], Еллен Касіредді[4], Рен Чен Мін[4], Дівія Пушкарна[4], Мір-Масуд Пурахмат[4], Аймерік Маю[5]

[1]Санофі, Франкфурт-на-Майні, Німеччина
[2]Санофі, Бріджуотер, Нью Джерсі, США
[3]Санофі, Шиї-Мазарен, Франція
[4]Евідіно Ауткамз Рісерч Інк., Ванкувер, Британська Колумбія, Канада
[5]Санофі, Париж, Франція

Метою цього дослідження було описати людський та економічний тягар у неформальних опікунів дітей, підлітків та молодих дорослих у яких нещодавно діагностовано цукровий діабет першого типу (ЦД1Т).

Методи: систематичний огляд літератури (СОЛ) було проведено з використанням баз MEDLINE®, Embase®, і PsycInfo® (дата пошуку: 7-го грудня, 2021) з метою виявлення клінічних та спостережних досліджень, які оцінювали людський тягар у неформальних опікунів дітей, підлітків та молодих дорослих віком 6-21 років, яким протягом трьох місяців діагностовано ЦД1Т.

Результати: до аналізу було включено чотири проспективні когортні дослідження та одне рандомізоване контрольоване дослідження (РКД). Вибірка опікунів становила від 59 до 191 осіб. Тривалість ЦД1Т складала від 2 до 6 тижнів. Серед батьків дітей віком ≤11 років, матері мали помірний ступінь тяжкості симптомів посттравматичного стресового розладу (середній бал: 11,9; стандартне відхилення [СВ]: 7,4), тоді як батьки мали легкий ступінь тяжкості (8,4; СВ: 6,2; p < 0,001; Шкала посттравматичного діагностичного показника). Матері відчували клінічно значущі симптоми (>5 балів) тривожності (середній бал: 7,5), соціальної дезадаптації (7,5) та соматичних симптомів (5,1; Загальний показник стану здоров'я [GHQ]-28). У батьків-чоловіків виявили лише клінічно значущу тривожність (5,5) та соціальну дезадаптацію (7,7; GHQ-28). Результати РКД показали середній бал страху перед гіпоглікемією 46,6 з 108 на момент встановлення діагнозу та 34,9 через 14 тижнів, вищий показник вказує на більший страх (Опитувальник щодо страху перед гіпоглікемією для батьків). Батьки дітей віком >11 років переживали клінічно значущу соціальну дезадаптацію (середній бал для матерів/батьків: 7,6/7,1) та тривожність (матері: 5,4; GHQ-28). При встановленні діагнозу батьки зазнавали помірного та сильного стресу, пов'язаного з ЦД1Т (≥5; середній бал: 6,3; СВ: 1,9) та відсутність або помірний стрес (4,5; СВ: 2,1) через 3 місяці. Жодне з включених досліджень не вивчало економічний тягар.

Висновки: цей СОЛ підкреслює, що батьки дітей та молодих дорослих, у яких нещодавно діагностували ЦД1Т, відчувають тягар опікунства, причому цей тягар є більшим у матерів, ніж у батьків. З огляду на недостатню кількість досліджень, є необхідність подальшого вивчення, для кращого зрозуміння людського тягару у цієї групи неформальних опікунів.

Ключові слова: цукровий діабет 1-го типу, опікуни, людський тягар, систематичний огляд літератури.

Humanistic Burden of Informal Caregivers of Children and Young Adults with Newly Diagnosed Type 1 Diabetes (T1D): A Systematic Literature Review (SLR)

Andriy Cherkas[1]*, Veleka Allen[2], Stephanie Bascle[3], Ellen Kasireddy[4], Ren Chen Min[4], Divya Pushkarna[4], Mir-Masoud Pourrahmat[4], Aymeric Mahieu[5]

[1]Sanofi, Frankfurt am Main, Germany
[2]Sanofi, Bridgewater, NJ, United States
[3]Sanofi, Chilly-Mazarin, France
[4]Evidinno Outcomes Research Inc., Vancouver, BC, Canada
[5]Sanofi, Paris, France

OBJECTIVES: To describe the humanistic and economic burden of informal caregivers of children, adolescents, and young adults newly diagnosed with T1D.

METHODS: An SLR was conducted in MEDLINE®, Embase®, and PsycInfo® (search date: December 7, 2021) to identify clinical and observational studies assessing the humanistic burden experienced by informal caregivers (i.e., persons who provide unpaid care) of children, adolescents, and young adults aged 6 to 21 who were diagnosed with T1D within three months.

RESULTS: Four prospective cohort studies and one randomized controlled trial (RCT) were included. Caregiver sample size ranged from 59 to 191. Duration of T1D was 2 to 6 weeks. Among parents of children aged ≤11 years, mothers had a moderate posttraumatic stress disorder symptom severity (mean score: 11.9; standard deviation [SD]: 7.4), while fathers experienced mild severity (8.4; SD: 6.2; p < 0.001; Posttraumatic Diagnostic Scale). Mothers experienced clinically significant symptoms (defined as score >5) of anxiety (mean score: 7.5), social dysfunction (7.5), and somatic symptoms (5.1; General Health Questionnaire [GHQ]-28). Fathers showed clinically significant anxiety (5.5) and social dysfunction (7.7; GHQ-28) only. Results from the RCT indicated a mean hypoglycemia fear score of 46.6 out of 108 at diagnosis and 34.9 after 14 weeks, with a higher score indicating greater fear (Hypoglycemia Fear Survey-Parents). Parents of children aged >11 years experienced clinically significant social dysfunction (mean score for mothers/fathers: 7.6/7.1) and anxiety (mothers: 5.4; GHQ-28). Parents experienced moderate to extreme diabetes-

Праці НТШ Медичні науки   Proc Shevchenko Sci Soc Med Sci   www.mspsss.org.ua
2023, Том 71, № 1   ISSN 2708-8634 (print)   ISSN 2708-8642 (online)   2023, Vol. 71, 1
Огляд   Review

specific stress (defined as score ≥5; mean score: 6.3; SD: 1.9) at diagnosis, and no to moderate stress (4.5; SD: 2.1) at 3 months. None of the included studies reported on economic burden.

CONCLUSIONS: This SLR highlights parents of children and young adults with newly diagnosed T1D experience caregiver burden, with a greater burden among mothers than fathers. Due to the paucity of evidence, further studies are warranted to better understand the humanistic burden among this group of informal caregivers**.**

Keywords: Type 1 Diabetes, Caregiver, Humanistic burden, Systematic literature review.

Introduction

T1D is an autoimmune disease characterized by the destruction of pancreatic beta cells by the immune system, leading to rapid decline of endogenous insulin production and secretion [1]. Very often onset of T1D occurs in childhood or adolescence with the peak between 10 and 15 years of age [2]. There is no disease-modifying therapy approved for newly diagnosed T1D so far, and disease management requires life-long insulin replacement therapy [3]. Despite the availability of injectable insulin and insulin pumps for the management of T1D, the burden of disease remains very high and people with T1D typically develop long term complications and have decreased life span expectancy [4]. Newly diagnosed T1D patients often require significant caregiving and this is particularly the case in children. Informal care is often provided by immediate family members, such as parents in the case of children with T1D. Studies globally have shown that caring for a child with T1D is associated with elevated levels of parental psychological distress [5]. This is particularly significant in an early period after diagnosis, as disease onset is sudden and unexpected in the vast majority of cases. Previous studies have identified this complex burden and recommended targeted psychosocial interventions for informal caregivers and care partners [6-8]. However, the significant and rapid developments in technology and disease management calls for an updated assessment of the humanistic and economic burden among informal caregivers of children, adolescents, and young adults living with T1D.

Methods

An SLR was conducted by searching MEDLINE®, Embase®, and PsycInfo® from database inception to December 6, 2021 (Figure 1) using MeSH terms and keywords for "type 1 diabetes" and "caregiver" or "parent". Additionally, gray literature searches were conducted (via Embase) for abstracts published in the American Diabetes Association (ADA) and European Association for the Study of Diabetes (EASD) conferences from 2020 to 2021. The review was performed in line with PRISMA 2020 guidelines without registration. Internal protocol was developed but not registered.

The overarching goal of this SLR was to describe and characterize the landscape of evidence on the humanistic burden of informal caregivers or parents of children, adolescents, and young adults (ages 6 to 21) who have been newly diagnosed with T1D within approximately three months. Specifically, we aimed to describe the impact of T1D symptoms on the caregiver burden.

After the exclusion of duplicates, two investigators reviewed all abstracts and proceedings identified through the searches and applied the following PICO criteria to assess eligibility:
- Studies were included if the population included informal caregivers (i.e., persons who provide unpaid care) of children, adolescents, and young adults aged 6 to 21 who were diagnosed with T1D within three months.
- Studies with any intervention or no intervention were included.
- Included studies had any comparator or no comparator.
- The full-text studies identified for eligibility included outcomes regarding informal caregiver perspective, symptoms, and burden.
- Study types were randomized and non-randomized clinical trials, observational studies, and qualitative research.

A preliminary conceptual framework, based on only studies included within the SLR, was developed to illustrate the humanistic burden associated with informal caregiving for people living with T1D.

Праці НТШ Медичні науки   Proc Shevchenko Sci Soc Med Sci   www.mspsss.org.ua
2023, Том 71, № 1   ISSN 2708-8634 (print)   ISSN 2708-8642 (online)   2023, Vol. 71, 1
Огляд   Review
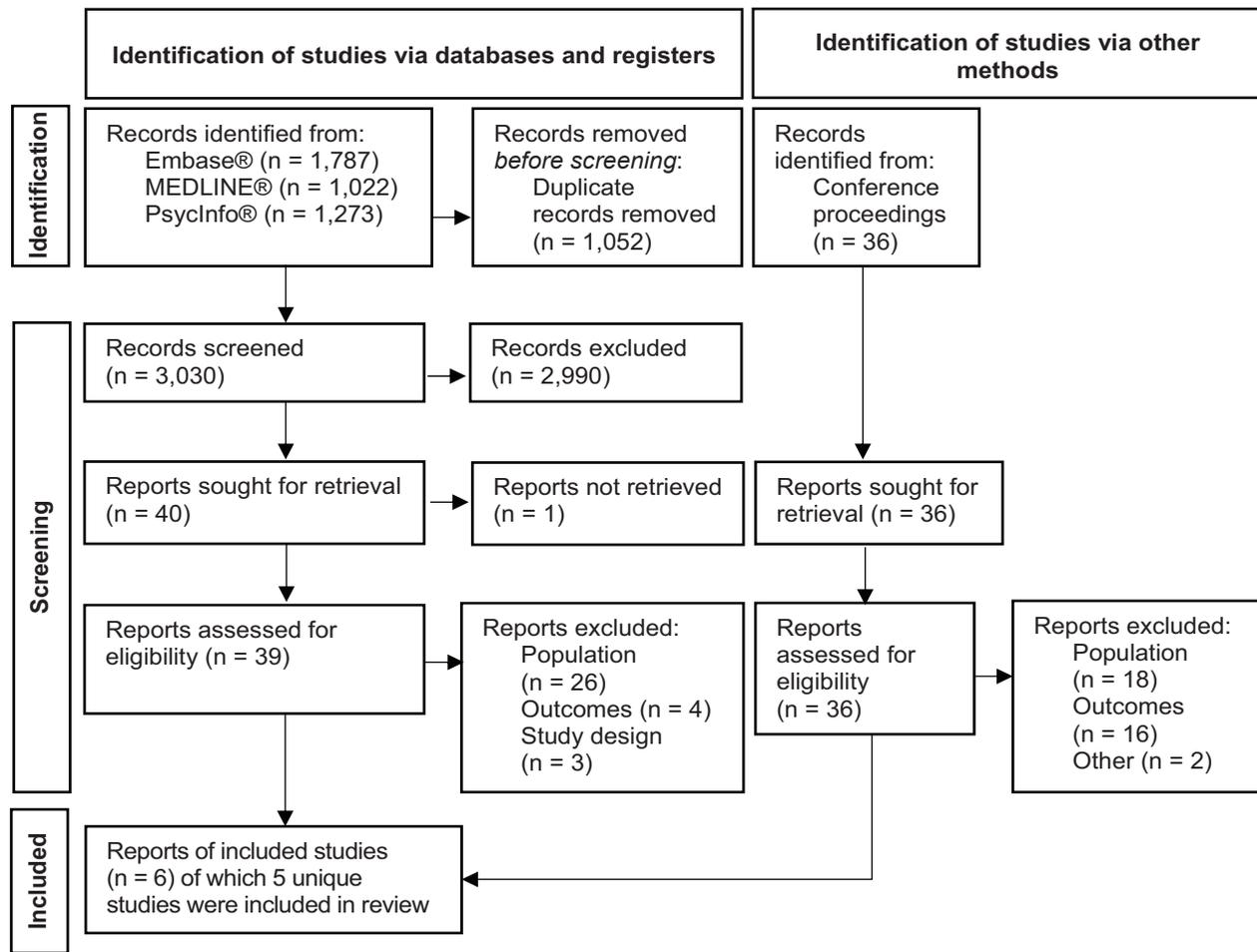
Figure 1. PRISMA flow diagram

Results

Of the five primary studies [9-13] included, four were prospective cohort studies and one was a randomized controlled trial (RCT) (Table 1). No qualitative studies were identified that met the eligibility criteria. As well, none of the included studies reported on economic burden. Three studies were conducted in the United States, one in Switzerland, and one in Australia. Study follow-up ranged from 14 weeks to 312 weeks (median: 48 weeks).

Patient Characteristics

The mean age of children with T1D across studies ranged from 7.6 years to 13.2 years (median: 9.1 years). The proportion of female children was reported across three studies and ranged from 39% to 53.7%. Most children were living with both their biological parents, 86.5% [9] and 84.9% [12]. Newly diagnosed with T1D was defined as within 2 weeks after diagnosis [9],

within the first 6 weeks of diagnosis [13] or within three months [10-12]. Baseline characteristics of children are summarized in Table 2.

Caregiver Characteristics

The mean age of informal caregivers was 38 years as per Sullivan-Bolyai 2015 [10], while another study by Kovacs 1990 [11] reported median maternal and paternal age as 37.6 years and 40 years, respectively (Table 2). The proportion of female caregivers ranged from 50.5% [9] to 100% [11]. Most informal caregivers had an intact family or were married.

Parents of Children Aged ≤11 Years

In Landolt 2005 [9] among parents of children aged ≤11 years, 22.4% and 79.6% of mothers, and 14.6% and 56.3% of fathers met the DSM-IV criteria for full posttraumatic stress disorder (PTSD) and subclinical PTSD, respectively. Mothers had a moderate PTSD symptom

Праці НТШ Медичні науки Proc Shevchenko Sci Soc Med Sci   www.mspsss.org.ua
2023, Том 71, № 1   ISSN 2708-8634 (print)   ISSN 2708-8642 (online)   2023, Vol. 71, 1
Огляд   Review

Table 1.

Baseline characteristics of children with T1D across included studies

First Author & Year		Mean age (years)	Sex, Femalen (%)	Ethnicity n (%)	Socio-economic Status n (%)	Time Since Diagnosis (weeks)	Living with both parents n (%)	Living with one parent n (%)
Sullivan-Bolyai 2015[10†]	*PETS-D*	8.9	NR	NR	NR	2	NR	NR
	Vignette only	9.1				2		
Landolt 2005[9]		10.5	22 (42.3%)	NR	Lower: 2 (3.8%) Middle: 39 (75.0%) Upper: 9 (17.3%) Unknown: 2 (3.8%)	6	45 (86.5%)	NR
Kovacs 1990[11]		11.1*	51 (53.7%)	White: 89 (94%) Black: 6 (6%)	Middle: 78 (82%)	2-3	78%	NR
Northam 1996[12]		7.6	NR	NR	Lower: 30 (28.3%) Middle: 57 (53.8%) Upper: 19 (17.9%)	3	90 (84.9%)	14 (13.2%)
Yi-Frazier 2018[13]		13.2	23 (39%)	NR	NR	6	NR	NR

* Median.
† The study by Sullivan-Bolyai et al. included two intervention arms and reported characteristics stratified by intervention arm.
NR: Not reported; PETS-D: Parent Education Through Simulation–Diabetes using human patient simulation.

Table 2.

Baseline characteristics of informal caregivers across included studies

First Author & Year		Median age (years)	Sex, Female n (%)	Marital status n (%)	Educational level n (%)	Other characteristics n (%)
Sullivan-Bolyai 2015[10†]	*PETS-D*	38	59 (60.2%)	Married: 63 (64.3%); Significant other: 16 (16.3%); Divorced/ separated: 12 (12.2%); Single: 7 (7.1%)	<High school or missing: 20 (20.4%); Completed high school: 28 (28.6%); Some college: 17 (17.3%); College: 20 (20.4%); Postgraduate: 13 (13.3%)	NR
	Vignette only		55 (59.1%)	Married: 62 (66.7%); Significant other: 12 (12.9%); Divorced/ separated: 9 (9.7%); Single: 10 (10.8%)	<High school or missing: 15 (16.1%); Completed high school: 27 (29%); Some college: 27 (29%); College: 15 (16.1%); Postgraduate: 9 (9.7%)	
Landolt 2005[9]		NR	49 (50.5%)	NR	NR	NR
Kovacs 1990[11]		Maternal: 37.6; Paternal: 40.7	95 (100%)	Intact family: 74 (78%)	NR	Physical health, Excellent or good: 88 (93%)
Northam 1996[12]		NR	NR	NR	NR	NR
Yi-Frazier 2018[13]		NR	NR	NR	Less than college: 27 (46%)	Income ($100k+): 30 (51%)

† The study by Sullivan-Bolyai et al. included two intervention arms and reported characteristics stratified by intervention arm.
NR: Not reported; PETS-D: Parent Education Through Simulation–Diabetes using human patient simulation.

Праці НТШ Медичні науки
2023, Том 71, № 1   ISSN 2708-8634 (print)
Огляд

Proc Shevchenko Sci Soc Med Sci   www.mspsss.org.ua
ISSN 2708-8642 (online)   2023, Vol. 71, 1
Review

severity (mean score: 11.9; standard deviation [SD]: 7.4), while fathers experienced mild severity (8.4; SD: 6.2) as measured by the Post-traumatic Diagnostic Scale. This difference was statistically significant ($p < 0.001$).

Northam 1996 [12] examined psychosocial and family functioning in parents of children with newly diagnosed T1D within 3 weeks after discharge from hospitalization. Symptoms of anxiety, social dysfunction, depression, and somatic symptoms were measured using the General Health Questionnaire (GHQ-28). Mothers experienced clinically significant symptoms (defined as score >5) of anxiety (mean score: 7.5), social dysfunction (7.5), and somatic symptoms (5.1), while fathers showed clinically significant anxiety (5.5) and social dysfunction (7.7) only.

Sullivan-Bolyai 2015 [10] examined the efficacy of the Parent Education Through Simulation–Diabetes (PETS-D), which is a series of parent education vignette sessions using human patient simulation, and parent education sessions using vignettes only. Results from the RCT indicated that caregivers in both intervention groups experienced a greater fear of hypoglycemia at diagnosis as measured by the Hypoglycemia Fear Survey for Parents (HFS-P), which decreased over time. At diagnosis, both intervention groups showed similar levels of fear, and at 6 and 14 weeks, levels of fear in caregivers in the PETS-D intervention group were slightly higher than those in the vignette only intervention group. Additionally, among a subgroup of informal caregivers with children younger than 6 years old, fear of hypoglycemia was significantly higher in the PETS-D intervention group than in the vignette only intervention group over time ($p = 0.03$).

Parents of Children Aged >11 Years

Kovacs 1990 [11] investigated if mothers of children aged >11 years with newly diagnosed T1D experienced symptoms of depression. The mean Beck Depression Inventory (BDI) score for mothers 2-3 weeks after receiving their child's diagnosis was 8.75 (SD: 7.62), indicating the mothers were not clinically depressed (BDI scores range from 0 to 63, with a score between 0 and 9 indicating that a person is not depressed).

Northam 1996 [12] showed that parents of children aged >11 years experienced clinically

significant (GHQ score of greater than 5) social dysfunction as measured by GHQ-28 with a mean score of 7.6 for mothers and 7.1 for fathers. In addition, mothers showed clinically significant symptoms of anxiety (mean: 5.4).

Yi-Frazier 2018 [13] measured acute diabetes-specific stress by asking caregivers "What is your overall stress level about your child's diabetes right now?" on a Likert scale from 1 to 10, with a score of 1 indicating not at all stressed, a score of 5 moderately stressed, and a score of 10 extremely stressed. At time of diagnosis, the mean diabetes-specific stress score as rated by informal caregivers was 6.4, and this decreased to 3.5 at 3 months.

Preliminary Conceptual Framework on Caregiver Burden

Relevant burden and impact concepts identified from the included studies were used to develop a preliminary conceptual framework of the caregiver burden in newly diagnosed T1D. Burden and impacts were categorized under overarching categories of factors, including (i) treatment factors, (ii) psychosocial factors, (iii) caregiver emotional functioning, (iv) disease-related factors, and (v) sociodemographic factors (Figure 2):

(i)   Treatment factors include parent education through simulation (n = 1) and one-to-one education (n = 1).
(ii) Psychosocial factors include parental resilience (n = 1), parental self-efficacy (n = 1), parental threat appraisal (n = 1), and family functioning: adaptability and cohesion (n = 1).
(iii) The overarching category of caregiver emotional functioning includes seven dimensions, and in particular anxiety (n = 2), depression (n = 2), and others.
(iv) Disease-related factors include length of hospital stay (n = 1) and patient compliance (n = 1).
(v)   Sociodemographic factors include the parent role: mother or father (n = 1) and patient age (n = 1).

Discussion

The aim of this SLR was to describe and characterize the landscape of evidence on the humanistic and economic burden of informal caregivers or parents of children, adolescents, and young adults (ages 6 to 21), who have been newly diagnosed with T1D within ap-

Праці НТШ Медичні науки
2023, Том 71, № 1   ISSN 2708-8634 (print)
Огляд

Proc Shevchenko Sci Soc Med Sci   www.mspsss.org.ua
ISSN 2708-8642 (online)   2023, Vol. 71, 1
Review

Psychosocial factors
- Parental resilience (n = 1)
- Parental self-efficacy (n = 1)
- Parental threat appraisal (n = 1)
- Family functioning: adaptability and cohesion (n = 1)

Disease-related factors
- Length of hospital stay (n = 1)
- Patient compliance (n = 1)

Treatment factors
- Parent education through simulation (n = 1)
- One-to-one education (n = 1)

Caregiver emotional functioning
- Anxiety (n = 2)
- Depression (n = 2)
- Posttraumatic stress disorder (n = 1)
- Social dysfunction (n = 1)
- Fear of hypoglycemia (n = 1)
- Diabetes-specific stress (n = 1)
- Somatic comorbidities (n = 1)

Sociodemographic factors
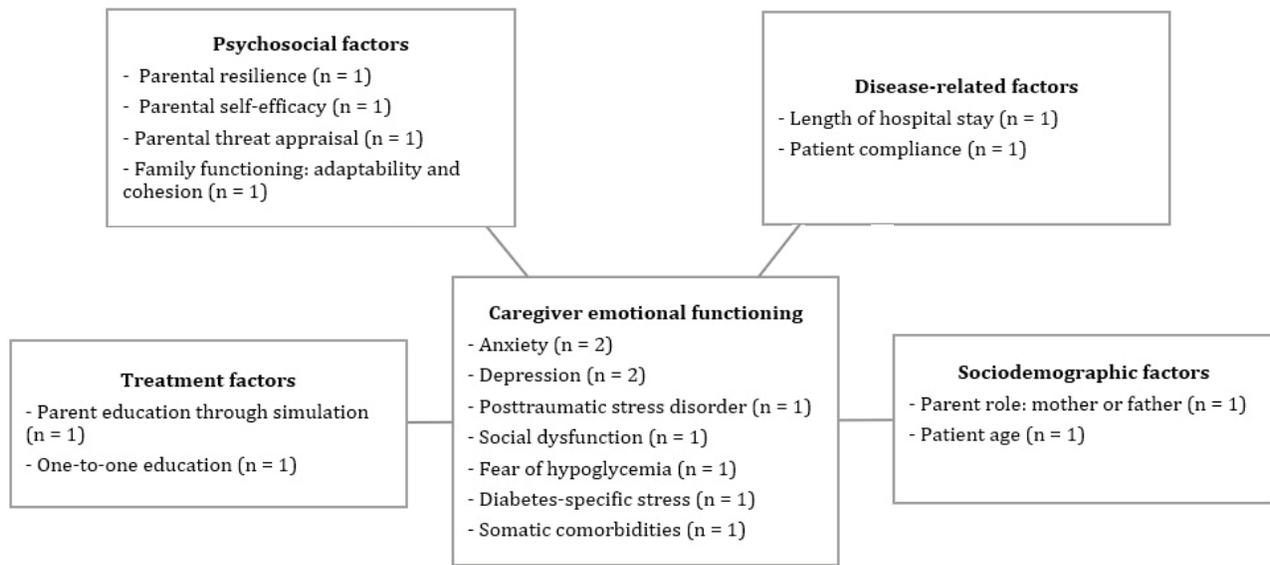- Parent role: mother or father (n = 1)
- Patient age (n = 1)

Figure 2. Preliminary conceptual framework of informal caregiver burden in newly diagnosed T1D (n = 5)

proximately three months. The SLR captured a small number of studies, the majority of which were single-center prospective cohort studies and conducted in the United States. Across the included publications, children with T1D had a median age of 10.5 years (ranging from 7.6 to 13.2) and were mostly male. Included informal caregivers of children with T1D were mostly middle-aged and female. Most of the caregivers had an intact family or were married.

In terms of informal caregiver burden outcomes, measures used varied widely across studies. Amongst parents of children aged 11 years or younger, parents showed mild symptoms of PTSD and clinically significant symptoms of anxiety, social dysfunction, and somatic symptoms. For both mothers and fathers, fear of hypoglycemia was highest at diagnosis and decreased over time within three months. Amongst parents of children older than 11 years, parents showed clinically significant symptoms of anxiety and social dysfunction. No signs of depression were noted.

In addition, a preliminary conceptual framework of caregiver burden in newly diagnosed T1D was developed using the five included studies. Concepts identified included treatment factors, psychosocial factors, disease-related factors, and sociodemographic factors. To the best of our knowledge, there is no other similar conceptual framework for a similar population available in the literature. This framework can

act as a starting step to understand the dynamics of disease burden for this population, and can be further developed and validated by organizing focus groups with patients, caregivers, and healthcare providers.

The present review had several strengths. Firstly, all stages of the review were carried out in accordance with standard recommendations for the conduct of SLRs [14,15]. Secondly, the literature search and screening were comprehensive. Although the final evidence base was small, all main databases and conference proceedings were covered during the searches and study selection. However, this review is not without limitations. Firstly, there was a paucity of evidence on the humanistic burden to informal caregivers within the short period of time just after diagnosis. This is despite the evidence that the level of stress and psychological burden typically peaks shortly after diagnosis [9,11,12,13]. Furthermore, none of the included studies reported on economic burden, indicating an evidence gap regarding newly diagnosed T1D. The caregiver burden outcome measures also varied widely across included studies, and only one study examined an intervention for caregivers, leading to difficulty in comparing findings across studies. Additionally, some dimensions, such as intensity of children diabetes, experience of disease from caregivers, or treatment perspectives were not reported in literature. Finally, the preliminary conceptual framework that was de-

Праці НТШ Медичні науки
2023, Том 71, № 1   ISSN 2708-8634 (print)
Огляд

Proc Shevchenko Sci Soc Med Sci   www.mspsss.org.ua
ISSN 2708-8642 (online)   2023, Vol. 71, 1
Review

veloped based on the included literature is the first preliminary conceptual framework analyzing the humanistic burden of caregivers of pediatric, adolescent, and young adult patients with newly diagnosed T1D. However, the preliminary conceptual framework has limitations because of the small number of included studies. Certain concepts may be missing from the preliminary conceptual framework as they were not identified in the current evidence base, including caregiver and patient characteristics and coping strategies. Additionally, the current conceptual framework requires more investigation with patients, caregivers, and healthcare providers to understand the dynamic of caregiver burden.

Due to these limitations, any conclusions regarding the findings related to informal caregiver burden and predictors of burden need to be interpreted cautiously.

Conclusions
Overall, this SLR highlights that parents of children, adolescents, and young adults with newly diagnosed T1D experience caregiver burden, with mothers experiencing a greater burden than fathers. Informal caregiver burden was found to be highest at diagnosis, with a slight decrease observed over time. Due to the paucity of evidence, our review uncovered existing gaps in the knowledge, and need of systematic approach to evaluate psychological and economic burden of T1D. This could become even more important in the future with development of new disease-modifying therapies and further improvement of technology in the field of T1D.

References

1. Atkinson, M. A., Eisenbarth, G. S., & Michels, A. W. Type 1 diabetes. The Lancet, 2014;383(9911), 69-82.
2. Gregory GA, Robinson TI, Linklater SE, Wang F, Colagiuri S, de Beaufort C, Donaghue KC, Magliano DJ, Maniam J, Orchard TJ, Rai P. Global incidence, prevalence, and mortality of type 1 diabetes in 2021 with projection to 2040: a modelling study. The Lancet Diabetes & Endocrinology. 2022 Oct 1;10(10):741-60.
3. DiMeglio A, Molina BE, Oram RA. Type 1 diabetes. Lancet. The Lancet. 2018;391(10138):2449-62.
4. White NH. Long-term outcomes in youths with diabetes mellitus. Pediatric Clinics. 2015 Aug 1;62(4):889-909.Kimbell B, et al. BMC pediatrics. 2021; 21(1):160.
5. Liu S, Leone M, Ludvigsson JF, Lichtenstein P, D'Onofrio B, Svensson AM, Gudbjörnsdottir S, Bergen SE, Larsson H, Kuja-Halkola R, Butwicka A. Association and Familial Coaggregation of Childhood-Onset Type 1 Diabetes With Depression, Anxiety, and Stress-Related Disorders: A Population-Based Cohort Study. Diabetes Care. 2022 Sep;45(9):1987-93.
6. Kimbell B, et al. Parents' experiences of caring for a young child with type 1 diabetes: a systematic review and synthesis of qualitative evidence. BMC pediatrics. 2021; 21(1):160.
7. The Hormone Foundation. Diabetes Caregivers Needs Assessment Survey – Executive Summary. 2010.
8. Whittemore R, et al. Psychological experience of parents of children with type 1 diabetes: a systematic mixed-studies review. The Diabetes educator. 2012; 38(4):562- 579.
9. Landolt MA, et al. Prospective study of posttraumatic stress disorder in parents of children with newly diagnosed type 1 diabetes. Journal of the American Academy of Child & Adolescent Psychiatry. 2005; 44(7):682-689.
10. Sullivan-Bolyai S, et al. PETS-D: impact on diabetes management outcomes. The Diabetes educator. 2015; 41(5):537- 549.
11. Kovacs M, et al. Psychological functioning among mothers of children with insulin-dependent diabetes mellitus: a longitudinal study. Journal of Consulting and Clinical Psychology. 1990; 58(2):189-195.
12. Northam E, et al. Psychosocial and family functioning in children with insulin-dependent diabetes at diagnosis and one year later. Journal of Pediatric Psychology. 1996; 21(5):699-717.
13. Yi-Frazier JP, et al. Trajectories of acute diabetes-specific stress in adolescents with type 1 diabetes and their caregivers within the first year of diagnosis. Journal of Pediatric Psychology. 2018; 43(6):645-653.
14. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Annals of internal medicine. 2009;151(4):264-269.
15. Higgins JPT, Altman DG, Gøtzsche PC, et al. The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. BMJ. 2011;343:d5928.