Journal of Pediatric Nursing xxx (xxxx) xxx

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Resilience in adolescents with type 1 diabetes: An integrative review

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ARTICLE INFO

Article history:
Received 7 March 2024
Revised 9 June 2024
Accepted 9 June 2024
Available online xxxx

Keywords:
Adolescent
Type 1 diabetes
Resilience
Review

ABSTRACT

Problem: Despite advances in diabetes technology, many adolescents with type 1 diabetes (T1D) cannot achieve target metabolic control. Resilience is associated with better outcomes in diabetes care.
The aim of this review is to synthesize studies on resilience in adolescents with T1D, particularly how the concept of resilience has been explored.
Methods: This integrative review was carried out according to Whittemore and Knafl's framework. A systematic search was conducted in the CINAHL, PubMed/Medline and PsycInfo databases. Eligibility criteria included studies on resilience in adolescents with T1D, aged 13 to 18 years, that were published in English in peer-reviewed scientific journals. The Mixed Methods Appraisal Tool was used to assess study quality.
Results: The review included twenty-four studies. Resilience was defined as the ability or capacity, or the process, to maintain physical and psychological well-being despite exposure to significant stressors or distress events. Diabetes resilience was defined as achieving positive psychosocial and health outcomes despite the challenges of living with T1D.
Studies were quantitative ($n = 21$), qualitative ($n = 1$) and mixed methods ($n = 2$). Six resilience instruments were found. The DSTAR-Teen was the most used and the only instrument for adolescents with T1D.
Conclusions: This review highlighted the need for an explicit definition of the concept of resilience because previous studies used different definitions or lacked a definition. In the future, a more precise concept analysis of resilience in adolescents with T1D is warranted.
Implications: The DSTAR-Teen is a promising resilience measure with good psychometric properties for further studies in adolescents with T1D.

Introduction

Type 1 diabetes (T1D) is one of the most common chronic conditions in children and adolescents (Miller et al., 2016). Approximately 1.52 million children and adolescents under the age of 20 are living with T1D (IDF Diabetes Atlas, 2022). In 2021 an estimated 149,500 adolescents under the age of 20 and 108,300 children under the age of 15 will be diagnosed with T1D (Ogle et al., 2022). Finland has the world's highest incidence (52.2/100,000 per year) of T1D in children aged 0–14 (Knip, 2021; Ogle et al., 2022), followed by Sweden (44.1) and Kuwait (41.7) (Ogle et al., 2022).

Despite advances in diabetes technology, many adolescents with T1D cannot achieve target metabolic control (Mcknight et al., 2015; Survonen et al., 2019). Hormonal changes and developmental challenges of puberty may complicate diabetes management (Chowdhury, 2015). Adolescents may need more support to handle their diabetes well. Adolescents with T1D face challenges in everyday life because T1D requires many self-care activities: monitoring blood glucose levels and administering insulin, diet and exercise (Elsayed et al., 2023). The aim of diabetes management is to ensure the well-being, normal growth, and development of children and adolescents and to prevent complications (*Insulin Deficiency Diabetes: Current Care Guidelines*, 2022).

Resilience in societies manifests itself as building strength and maintaining service and function in the face of adversity; resilient individuals are the core of building resilient communities (Joossens et al., 2022). People facing challenges can become resilient in this part of their lives. Resilience is not seen as a fixed characteristic of an individual because resilience can be developed (Hilliard et al., 2012; Lord et al., 2015). However, there is no scientific consensus on how to define resilience, whether it is a state or a process (Morse et al., 2021). According to American Psychological Association (2023) resilience is defined as

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https://doi.org/10.1016/j.pedn.2024.06.007

Please cite this article as: A. Survonen, R. Suhonen and K. Joronen, Resilience in adolescents with type 1 diabetes: An integrative review, Journal of Pediatric Nursing, https://doi.org/10.1016/j.pedn.2024.06.007

"the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral flexibility and adjustment to external and internal demands". Adolescent resilience has also been investigated both as an outcome of adaptation and as a process of adaptation (Olsson et al., 2003). In nursing and health care, resilience is defined as a process that enables an individual to recover from an illness or accident and as a state that can be achieved (Morse et al., 2021). In this study, resilience in adolescents with T1D is defined as the process or ability to recover from stressful events while living with a long-term condition (Babic et al., 2020; Morse et al., 2021).

Diabetes resilience is defined as "achieving one or more positive outcomes despite exposure to significant risk or adversity." Resilience has two components: adversity and protection. The impact of risks and assets on resilient diabetes-related outcomes may be reduced or enhanced by salient diabetes-specific protective processes. Resilient adolescents do well with diabetes management, glycemic control and health-related quality of life (HRQOL), while others facing similar risks struggle (Hilliard et al., 2012). Resilience also has a positive impact on emotional well-being (Hilliard et al., 2015).

Previously, nursing studies on adolescents with T1D have primarily focused on compliance and adherence (Datye et al., 2015; Kyngäs, 2000, 2007; Kyngäs & Rissanen, 2001) with patients considered recipients of medical decisions and prescriptions of self-management. There is a need for a different approach in adolescents' diabetes care. Nowadays, the aim of diabetes education is to support patients to become empowered and active in the decision-making of diabetes management (Funnell & Anderson, 2003; *Insulin Deficiency Diabetes: Current Care Guidelines*, 2022; Lindholm Olinder et al., 2022).

Research on resilience in diabetes care has been carried out since the early 2000s (Steinhardt et al., 2009; Winsett et al., 2010; Yi et al., 2008) and has increased in recent years (Lehmann et al., 2024; Pate et al., 2022; Skedgell et al., 2021; Wojujutari et al., 2024), but the definition of the concept still seems to be rather heterogeneous and unstable. Moreover, there are many measures of resilience, but to our knowledge, no comprehensive understanding of these measures in adolescents with T1D has been previously reported, but it is needed to find a valid and reliable measure to use in further studies. The aim of this integrative review was to synthesize studies on resilience in adolescents with T1D, particularly how the concept of resilience has been explored.

Methods

An integrative review of the literature was carried out according to Whittemore and Knafl (2005), including problem identification, literature search, data evaluation, data analysis, and presentation. The Preferred Reporting Items for Systematic Review and Meta-Analyses was followed (Page et al., 2021). Content analysis and narrative synthesis were performed. The protocol of this integrative review was registered on PROSPERO (CRD42022299630).

Problem identification

The aim of this review is to clarify the definition of resilience in adolescents with T1D because the concept of resilience has been used in various ways and operationalized in different instruments to measure resilience in studies of adolescents with T1D. The review aimed to respond to two research questions: How resilience has been defined and described in previous studies of adolescents with T1D and how resilience has been explored and measured in previous studies of adolescents with T1D.

Literature search

A search of the three electronic databases CINAHL, PubMed/Medline and PsycInfo was conducted in March 2024. Search terms consisted of medical subject headings (MeSH), and free search terms of type 1 diabetes, adolescent, and resilience were used to search the databases, with article titles, abstracts and body all searched. The search strategy was developed in consultation with a medical librarian. To increase the likelihood of identifying all relevant studies, the reference lists of all retrieved articles were hand-searched. Two reviewers independently selected studies investigating resilience. Selection of articles was based on the inclusion and exclusion criteria and was conducted independently by two researchers. Disagreements were resolved by consensus.

The inclusion criteria for this review were: (1) studies focusing on resilience in adolescents with type 1 diabetes, aged between 13 and 18 years; (2) studies in which the median age of the adolescents was between 13 and 18, or at least half of the participants were in this age group, and (3) studies published in English in peer-reviewed scientific journals.

Studies were excluded if the age group of participants was not suitable ($n = 14$) for the following reasons: because all study participants were ≥ 18 years ($n = 8$), the median age was >18 years (n = 1), the majority of the participants were > 18 years ($n = 2$), and the median age was under 13 years ($n = 3$). Studies that did not address resilience ($n = 6$) were also excluded: studies on diabetes experience (n = 1), adolescents' transition to adult care (n = 1), depression and distress (n = 1), positive well-being (n = 1), adolescents' and parents' perspectives on T1D (n = 1), and impact of T1D on self (n = 1). Studies on type 2 diabetes (n = 2), interventions for professionals (n = 1) and parents (n = 1), theoretical articles (n = 2), dissertations (n = 1) and duplicates (n = 1) were also excluded. One study written in Chinese was excluded.

Quality appraisal

In the third phase of the review, two authors independently evaluated the methodological quality of selected articles ($n = 25$) using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). The first screening question on research questions was interpreted as "yes" if the aim of the study was clearly defined. One study (Agustini et al., 2019) was rejected for low quality because the aim of the study was not clearly stated. For each study, an overall quality score was calculated as 0, 20, 40, 60, 80 or 100%, and the criterion items not met using the MMAT are included in Table 1. Eight studies (8/24, 33%) met 100% of the quality criteria, eight studies (8/24, 33%) met 80%, seven studies (7/24, 29%) met 60% and one study had the lowest score of 40%.

Data analysis

Data analysis includes data reduction, data display, data comparison, conclusion drawing and verification (Whittemore & Knafl, 2005). To analyze the methodology of the selected articles, the author(s), year of publishing, country, purpose, sample, design, and methods were tabulated (Table 1). Information about the instruments used in the quantitative studies was also tabulated: the name, developer(s), the content of the instruments, type of scales, and the reported reliability and validity of the instrument (Table 2). After analyzing the methodological content of the articles, the material related to resilience in adolescents with T1D was extracted, analyzed, and interpreted using qualitative inductive content analysis to find the definition of resilience.

Results

The electronic search of all databases yielded a total of 205 records. After removing duplicates, titles and abstracts of 134 articles were screened and 25 full texts were selected (see Fig. 1). One study (Agustini et al., 2019) was rejected for low quality. The 24 studies included in this review were published between 2010 and 2022 (Fig. 2). Most of the studies were published in 2015–2018 ($n = 14$) and in 2022 ($n = 3$). Fifteen studies were conducted in the USA (Table 1), two in China (Luo et al., 2019; Xu et al., 2020), and one each in

Table 1
Summary of studies ($n = 24$) included in the review.

Author(s) Year Country	Purpose	Sample Age (mean)	Research Design	Methods	MMAT Quality Appraisal
Cassarino-Perez and Dell'Aglio (2015) Brazil	To investigate resilience processes in adolescents with T1D identifying risk and protective factors through multiple case studies.	$n = 3$, $n = 2$ boys $n = 1$ girl 13 to 14 years	Qualitative and cross-sectional research, with a multiple case study design	*Semi-structured interviews:* the adolescents' data on healthcare, coping with the disease, benefits and losses of having diabetes, personality characteristics and future plans. *The Five Field Map:* support network divided into family members, friends, formal contacts, school, and relatives.	60% (3/5) Criteria 1.4, 1.5
Chambers et al. (2022) USA	To evaluate the feasibility, acceptability, and preliminary efficacy of a team-based intervention for youth with T1D with suboptimal glycemia, as detected based on the measurement of HbA1C	$n = 40$ $n = 21$ boys $n = 19$ girls 9 to 18 years Boys 14.4 ± 2.1. Girls 13.7 ± 2.5	Nonblinded pilot study, multidisciplinary intervention	A certified diabetes care and education specialist integrated medical management, while reinforcing physical, emotional, and behavioral health, connected with families to set and monitor goals and reviewed medication adjustments. The assessment of *feasibility:* enrollment target *Acceptability*: retention rates, *Preliminary efficacy:* changes in HbA1C, QOL, diabetes-related strengths and resilience, hospital admissions, emergency room visits, and missed school days.	100% (5/5)
Demirtaş et al. (2022) Turkey	To adapt the DSTAR-Teen into Turkish and investigate its psychometric properties in adolescents with T1DM living in Turkey.	$n = 120$ 14 to 18 years (mean 15.23)	Descriptive, methodological study	Forward and backward translation of the instrument. The data were evaluated using Cronbach's alpha coefficients, factor analyses, test-retest correlation, and item-total score correlations.	80% (4/5) Criteria 4.2
Hayes et al. (2017) England	Personal resilience was studied in relation to perceived support and perceived stress in students aged between 11 and 16 managing school demands and type 1 diabetes.	$n = 54$ $n = 35$ female $n = 19$ male 11 to 16 years (mean 13.7) Six students were interviewed in the qualitative phase.	A mixed method design employing a sequential explanatory strategy	Phase I: three quantitative measures individually or in small group sessions led by the second author. A semi-structured interview schedule was developed to elicit pupils' views.	60% (3/5) Criteria 5.4, 5.5
Hilliard, Hagger, et al. (2017) Australia	To investigate relations among diabetes strengths and resilient outcomes in the context of psychological and family risk factors	$n = 471$ 13 to 19 years (mean 15.7)	Cross-sectional survey The data from the Diabetes Management and Impact for Long-term Empowerment and Success (MILES) Youth Survey	Measures: diabetes-related strengths, risk factors (depressive/anxiety symptoms, family conflict), and resilient outcomes (SMBG frequency, general QOL, HbA1c).	80% (4/5) Criteria 4.4
Hilliard, Iturralde, et al. (2017) USA	To evaluate the psychometric properties of a newly developed measure of diabetes-specific strengths in adolescents with T1D	$n = 260$ 14 to 18 years (mean 15.7) and caregivers	Cross-sectional survey Baseline data from a clinical trial (Weissberg-Benchell et al., 2016)	Data from a behavioral intervention trial were analyzed to evaluate psychometric properties of the 12-item self-reported Diabetes Strengths and Resilience measure for adolescents (DSTAR-Teen).	80% (4/5) Criteria 4.4
Hood et al. (2018) USA	To report 1-year outcomes of the Supporting Teens Problem Solving (STePS) study, a randomized controlled trial comparing a distress and depression prevention program with a diabetes education program for adolescents with T1D.	$n = 264$ 14 to 18 years (mean 15.74)	Randomized controlled trial	Interventions lasted 4.5 months. Assessments at baseline, and 4.5, 8, 12, and 16 months. Outcomes: diabetes distress (DD), depressive symptoms, resilience, diabetes self-management, and glycemic control. Resilience: five different measures.	60% (3/5) Criteria 2.1, 2.4
Huston et al. (2016) USA	To verify structure of underlying measurement variables: Negative diabetes-related emotions (NDRE), emotion processing (EP), emotion expression (EE), benefit finding (BE), diabetes acceptance (DA), fitting in with friends (FI) and comfort in adjusting for diabetes in public (CA) among youth with diabetes.	$n = 243$ 11 to 16 years (mean 13.2)	Cross-sectional study	Pre-camp survey. Measures: demographic questionnaire, diabetes diagnosis date, previous camp attendance and questions on EE, EP, NDRE, BF, DA, FI and CA.	100% (5/5)
Jaser and White (2011) USA	To use a developmentally sensitive coping measure to explore how the use of specific coping strategies impacts resilience (i.e., quality of life, competence and metabolic control) in adolescents with T1D	$n = 30$ 10 to 16 years (mean 12.6) and their mothers	Survey/cross-sectional study Adolescents and their mothers also participated in a videotaped discussion of diabetes stress; these results are presented elsewhere (Jaser & Gray 2010)	Compas and colleagues' model of coping was used to examine the association between the use of specific types of coping strategies and indicators of resilience (i.e., competence, quality of life and metabolic control) in adolescents with T1D. Questionnaires on adolescents' coping strategy use, competence and quality of life.	60% (3/5) Criteria 4.1, 4.2
Lo et al. (2016) Taiwan	To construct a path model addressing the influences of individual characteristics, school support, resilience, and	$n = 238$ 13 to 18 years	Cross-sectional design study	A structured questionnaire Instruments:	80% (4/5) Criteria

(continued on next page)

Table 1 (*continued*)

Author(s) Year Country	Purpose	Sample Age (mean)	Research Design	Methods	MMAT Quality Appraisal
	self-care behaviors on glycated hemoglobin (HbA1c) and QoL among adolescents with T1D in Taiwan.	(mean 15.7)		Adolescent Resilience Scale School support scale Diabetes Quality of Life Youth Scale (C-DQOLY-SF)	4.2
Lord et al. (2015) USA	To describe positive affect (using both observations and self-report) as a protective process in adolescents with T1D and to examine the associations between positive affect, glycemic control, quality of life, and psychological symptoms.	$n = 93$ 10 to 16 years (mean 12.6) and mothers	Prospective, observational study	Questionnaires a videotaped interaction adolescents with their mothers	80% (4/5) Criteria 4.2
Lukács et al. (2018) Hungary	To investigate the influence of sex, age, diabetes duration, GC expressed by HbA1c, intensive insulin regimen, physical activity (PA), resilience (RS), and socioeconomic background on HRQoL	$n = 229$ 13 to 19 years (mean 15.35)	Multicenter quantitative correlational design study	Questionnaires: physical activity, resilience, HRQoL	100% (5/5)
Luo et al. (2019) China	To examine the effects of family functioning and resilience on self-management and glycemic control among youth with T1D and to determine whether resilience mediates the effects of family functioning on self-management and glycemic control.	$n = 204$ 8 to 24 years (mean 15.71)	Survey with a convenience sample	Measures: Family functioning, resilience, self-management and diabetes distress HbA1c DSTAR-Teen	80% (4/5) Criteria 4.2
Perfect and Jaramillo (2012) USA	To examine the role that resiliency and diabetes quality of life play in school functioning and glucose control among adolescents with diabetes.	$n = 45$ 13 to 17 years (mean 15.39)	Participants were recruited as part of a larger study, Integrating Medical and Mental Health Figure	Phase I: in-person visit included the consent process and the adolescent completing the BSI, the Diabetes Quality of Life-Youth (DQOL-Y), and questions about their experience with screening. Phase II: face-to-face assessment approximately 1 week later. The Beck Youth Inventories-2nd Edition (BYI-II), RSCA, National Institute of Mental Health-Diagnostic Interview Schedule for Children-IV-TR (used in parent study), and questions about their experience.	60% (3/5) Criteria 4.2, 4.4
Scott et al. (2022) USA	To investigate whether diabetes distress and resilience 3 months after diagnosis predicted yearly increases in A1C in youth with T1D starting at 1 year and up to 3 years later.	$n = 34$ 10 to 18 years (mean 13.21)	Follow-up analysis of a new onset diabetes in youth study	Measures: distress and resilience at baseline and 3 months following diagnosis. Multilevel modeling: A1C trajectories up to 3 years following diagnosis.	80% (4/5) Criteria 4.4
Shapiro et al. (2021) USA	To identify subgroups of adolescents with T1D who may be at risk for difficulty with diabetes management behaviors, glycemic control, and diabetes distress based on profiles of resilience processes.	n = 264 14 to 18 years (mean 15.7) resilience program ($n = 133$), diabetes education control ($n = 131$).	Data were from the Supporting Teen Problem Solving study RCT	Data collection at seven time points over 3 years and analyzed with latent profile analysis and latent growth curve modeling.	60% (3/5) Criteria 2.1, 2.4
Sivertsen et al. (2014) Norway	To compare symptoms of mental health problems and sleep and eating disturbances in adolescents with T1D and without T1D in a population-based sample.	$n = 9883$ 16 to 19 years (mean 17.9) 40 adolescents were classified as having T1D (prevalence 0.4%).	Population-based study. Data from the youth@hordaland study, a large population based study in Hordaland County	Self-reported data on both diabetes and a range of instruments assessing mental health symptoms, including depression, anxiety, obsessive-compulsive behaviors, hyperactivity, impulsivity, inattention, perfectionism, resilience, sleep problems and eating behavior.	100% (5/5)
Vesco et al. (2018) USA	To examine concordance and discordance between parent–adolescent report of diabetes-specific emotional distress and associations with A1C and diabetes-related strengths.	$n = 1216$ 12 to 18 years (mean 14.4) adolescent–parent dyads	Cross-sectional data. Sample originates from the second year of a larger study examining psychosocial outcomes of diabetes camps (Weissberg-Benchell & Rychlik, 2017).	Questionnaires: diabetes distress, diabetes strengths. Data collection via a secure online survey portal.	100% (5/5)
Walker et al. (2015) USA	To better understand the perspectives of youths with type 1 diabetes according to key demographic variables.	$n = 40$ 12 to 19 years (mean 15)	Exploratory study, mixed method study	Surveys were used to better understand the ways in which adolescents define and experience diabetes in everyday life. Youths were provided with disposable cameras and prompted to take five photographs each that captured what diabetes meant to them and to provide narratives to accompany their photo choices.	60% (3/5) Criteria 5.4, 5.5

Weissberg-Benchell et al. (2016) USA	To compare the effectiveness of a depression prevention, resilience promotion program with an advanced diabetes education program. To describe the study design, the intervention, and the baseline characteristics of the sample.	$n = 264$ 14 to 18 years (mean 15.7)	RCT- the description of study design, the intervention, and the baseline characteristics of the sample.	Each program consisted of 9 group-based sessions. The primary outcomes: depressive symptoms and glycemic control; secondary outcomes: resilience skills, diabetes management and adherence, and diabetes-specific distress.	100% (5/5)
Winsett et al. (2010) USA	To explore the concept of self-efficacy and resilience, two possible mediators influenced by attending camp.	$n = 81$ 10 to 16 years (mean 13.4)	Descriptive comparative pilot study	Questionnaires: self-efficacy and resilience.	100% (5/5)
Xu et al. (2020) China	To develop a Chinese version of the Diabetes Strengths and Resilience Measure for Adolescents (DSTAR-Teen) and evaluate its psychometric characteristics.	$n = 120$ 12 to 19 years (mean 16.3)	Prospective observational study.	Questionnaires. The DSTAR-Teen and the related psychosocial instruments to evaluate the reliability and validity. The DSTAR-Teen was adapted into a Chinese version prior to data collection.	40% (2/5) Criteria 4.1, 4.2, 4.5
Yi-Frazier et al. (2018) USA	To describe stress trajectories for newly diagnosed type 1 diabetes (T1D) in adolescents and their parents, explore whether resilience is associated with stress trajectories, and examine the effects of stress trajectories on diabetes-specific outcomes.	$n = 59$ 10 to 18 years (mean 13.2) adolescents and a primary caregiver	Longitudinal study	Stress and resilience were assessed using questionnaires every 3 months, and diabetes-specific outcomes (self-care, quality of life, and hemoglobin A1C) at 6 and 12 months. Parent and adolescent stress trajectories were identified using semiparametric group-based modeling.	100% (5/5)
Yi-Frazier et al. (2015) USA	To explore the association between personal resilience and distress, coping, and diabetes outcomes in 50 adolescents with type 1 diabetes	$n = 50$ 13 to 18 years (mean 15.62)	Survey with a purposive sample	Resilience was defined by a factor score derived from validated instruments measuring self-efficacy, optimism, and self-esteem. Variable- and person-focused methodologies were used to explore these associations.	80% (4/5) Criteria 4.2

Australia (Hilliard, Hagger, et al., 2017), Brazil (Cassarino-Perez & Dell'Aglio, 2015), England (Hayes et al., 2017), Hungary (Lukács et al., 2018), Norway (Sivertsen et al., 2014), Taiwan (Lo et al., 2016) and Turkey (Demirtaş et al., 2022).

Sample sizes ranged from 3 to 9883 adolescents. In one qualitative study, the sample size was three (Cassarino-Perez & Dell'Aglio, 2015); in quantitative studies ($n = 21$) sample sizes ranged from 30 (Jaser & White, 2011) to 9883 (Sivertsen et al., 2014); and in mixed method studies ($n = 2$) from 6 (Walker et al., 2015) to 54 adolescents (Hayes et al., 2017).

The definition of resilience was found in 14 studies (Cassarino-Perez & Dell'Aglio, 2015; Hood et al., 2018; Lo et al., 2016; Lord et al., 2015; Lukács et al., 2018; Luo et al., 2019; Perfect & Jaramillo, 2012; Scott et al., 2022; Shapiro et al., 2021; Weissberg-Benchell et al., 2016; Winsett et al., 2010b; Xu et al., 2020; Yi-Frazier et al., 2015; Yi-Frazier et al., 2018) and a definition of diabetes resilience in four studies (Demirtaş et al., 2022; Hilliard, Hagger, et al., 2017; Hilliard, Iturralde, et al., 2017; Vesco et al., 2018). Six studies (Chambers et al., 2022; Hayes et al., 2017; Huston et al., 2016; Jaser & White, 2011; Sivertsen et al., 2014; Walker et al., 2015) did not define the concept of resilience or diabetes resilience.

From the studies that included the definition of resilience or diabetes resilience, two studies (2/18, 11%) defined resilience very broadly as consisting of four constructs: a sense of hopefulness, an optimistic explanatory style, effective coping strategies, and positive problem-solving skills due to the complex construct of resilience (Hood et al., 2018; Weissberg-Benchell et al., 2016). In one study (Perfect & Jaramillo, 2012), the term of resiliency was used instead of resilience, a rarely used synonym.

Resilience was defined as *an ability* or *capacity* in nine studies (9/18, 50%) (Cassarino-Perez & Dell'Aglio, 2015; Lo et al., 2016; Lukács et al., 2018; Luo et al., 2019; Perfect & Jaramillo, 2012; Winsett et al., 2010a; Xu et al., 2020; Yi-Frazier et al., 2015; Yi-Frazier et al., 2018). Furthermore, resilience was defined as an *individual's coping ability* (Cassarino-Perez & Dell'Aglio, 2015) or *ability* (Luo et al., 2019; Perfect & Jaramillo, 2012; Winsett et al., 2010a) or *capacity* (Lo et al., 2016; Lukács et al., 2018; Xu et al., 2020; Yi-Frazier et al., 2015; Yi-Frazier et al., 2018) to maintain physical and psychological well-being despite exposure to significant stressors or distress events (Lo et al., 2016; Lukács et al., 2018; Luo et al., 2019; Perfect & Jaramillo, 2012; Yi-Frazier et al., 2015; Yi-Frazier et al., 2018) or as "ability to recognize personal strengths" (Winsett et al., 2010). Similarly, Yi-Frazier et al. (2018) also identified resilience as "*a protective resource*, reflecting self-perception of abilities to harness the resources needed for health."

Resilience was defined as *a process* in four studies (4/18, 22%) (Lord et al., 2015; Lukács et al., 2018; Scott et al., 2022; Shapiro et al., 2021). It was defined as a process that comprises protective skills and assets (Shapiro et al., 2021), positive adaptation (Lord et al., 2015), and harnessing resources (Lukács et al., 2018; Scott et al., 2022). When facing adversity, such as managing a complex medical condition like T1D, resilience refers to achieving positive emotional, behavioral, or health outcomes. One study reported that resilience processes for youth with T1D consist of individual, familial, and contextual systems (Shapiro et al., 2021).

A model/concept of *diabetes resilience* by Hilliard et al. (2012) was used in four studies (Demirtaş et al., 2022; Hilliard, Hagger, et al., 2017; Hilliard, Iturralde, et al., 2017; Vesco et al., 2018). In those articles, diabetes resilience was defined as *achievement* of positive psychosocial and health outcomes such as good quality of life, engagement in diabetes self-management and glycemic outcomes in the target despite the many challenges of living with T1D in adolescence (Demirtaş et al., 2022; Hilliard, Hagger, et al., 2017; Hilliard, Iturralde, et al., 2017).

Findings of the methodology of the studies

The studies were qualitative ($n = 1$), randomized controlled trials ($n = 2$), quantitative descriptive ($n = 19$) and mixed methods studies

Table 2
Summary of the instruments used in quantitative studies.

Instrument	Originally developers	Content	Scale	Usage	Reliability/validity
Adolescent Resilience Scale (ARS, *abbreviation used in this study)*	Chen (2007)	12 items: awareness of self-esteem, sense of mastery, and positive expectation	5-point Likert: 1 strongly disagree, 5 strongly agree	Lo et al. (2016)	Cronbach's alpha 0.90 ICC 0.86 Factor analysis: No. of factors 1 Explained variance 48.38% (Lo et al., 2016)
Connor-Davidson Resilience Scale (CD-RISC-10), 10-item version	Campbell-Sills & Stein (2007); Connor & Davidson (2003), 25 items)	10 items: patient perceptions of their own resilience	5-point Likert: 1 not true at all, 5 true nearly all of the time	Yi-Frazier et al. (2018) Scott et al. (2022)	Cronbach's alpha 0.83 (Yi-Frazier et al., 2018) N/A (Scott et al., 2022)
Diabetes Strengths and Resilience Measure for adolescents (DSTAR-Teen)	Hilliard, Hagger, et al. (2017)	12 items: Diabetes-related Confidence and Help with Diabetes Management	5-point Likert: 1 never, 5 almost always	Chambers et al. (2022) Hilliard, Iturralde, et al. (2017) Hilliard, Hagger, et al. (2017) Hood et al. (2018) Luo et al. (2019) Vesco et al. (2018) Weissberg-Benchell et al. (2016) Xu et al. (2020)	N/A (Chambers et al., 2022) Cronbach's alpha 0.88 (Hilliard, Hagger, et al., 2017) Cronbach's alpha 0.89 item-total correlations: r range = 0.55–0.78 (Hilliard, Iturralde, et al., 2017) N/A (Hood et al., 2018) Cronbach's alpha 0.88 (Luo et al., 2019) Cronbach's alpha 0.78 (Vesco et al., 2018) Cronbach's alpha 0.89 (Weissberg-Benchell et al., 2016) Cronbach's alpha 0.90, intraclass correlation coefficient = 0.98). test-retest reliability: ICC of 0.98 (95% CI: 0.95 to 0.99). (Xu et al., 2020)
Resiliency Scales for Children and Adolescents (RSCA)	Prince-Embury (2007)	64 items: three scales: sense of mastery (MAS), covering optimism, self-efficacy and adaptability; sense of relatedness (REL), covering relationships with others and emotional reactivity (REA), covering vulnerability to stress or impact of adversity. (Hayes et al., 2017) Hilliard, Iturralde, et al. (2017) used two scales: MAS and REL (44 items)	5-point Likert: 0 never, 1 rarely, 2 sometimes, 3 often, 4 almost always	Hayes et al. (2017) Hilliard, Hagger, et al. (2017) (Hilliard, Iturralde, et al., 2017) Hong et al. (2018) Weissberg-Benchell et al. (2016)	The coefficient alphas for the RES (resilience) and VUL (vulnerability) indexes ranged from 0.93 to 0.97. Across age ranges in the standardization sample, validity and test–retest reliability were >0.76 for the three scales (Hayes et al., 2017) Cronbach's alpha 0.97 (Hilliard, Iturralde, et al., 2017) (Hilliard, Iturralde, et al., 2017) N/A (Hood et al., 2018) Total score alpha = 0.97 Relational score alpha = 0.94 Mastery score alpha = 0.95 (Weissberg-Benchell et al., 2016)
Resilience Scale for Adolescents (READ)	Von Soest, Mossige, Stefansen, & Hjemdal (2010)	28 items: Personal Competence, Social Competence, Structured Style, Family Cohesion and Social Resources.	5-point Likert (not specified)	Sivertsen et al. (2014)	Cronbach's alpha 0.95 (Sivertsen et al., 2014)
Resilience Scale (RS)	Wagnild & Young (1993)	15 items No subscales.	7-point Likert: 1 strongly disagree, 7 strongly agree	Lukács et al. (2018) Winsett et al. (2010)	Cronbach's alpha 0.87 (Lukács et al., 2018) N/A (Winsett et al., 2010)

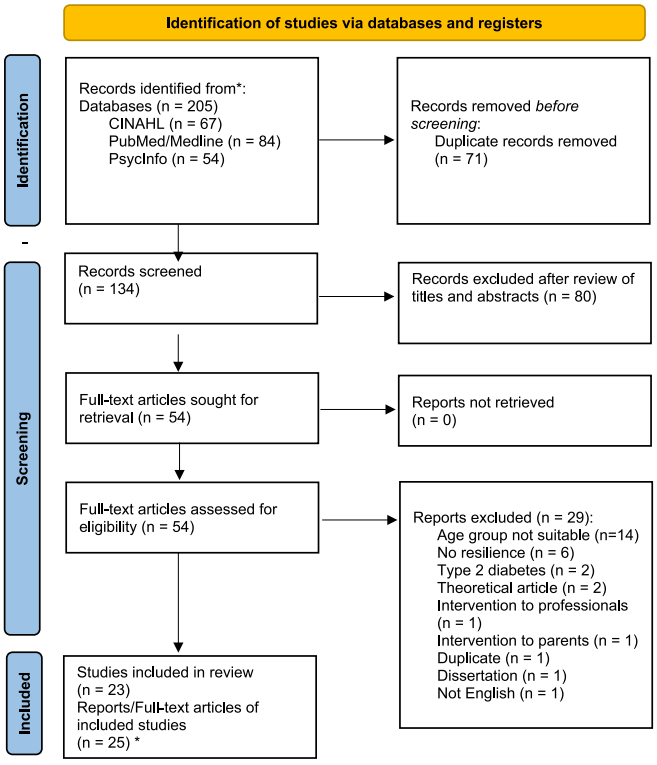

Fig. 1. PRISMA 2020 flow diagram.
*Same data (Hood et al., 2018; Shapiro et al., 2021; Weissberg-Benchell et al., 2016).
From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. https://doi.org/10.1136/bmj.n71 For more information, visit: http://www.prisma-statement.org/.

(n = 2). The *qualitative* study (Cassarino-Perez & Dell'Aglio, 2015) had a cross-sectional and multiple case study design, including semi-structured interviews.

Quantitative randomized controlled trials comprised two studies (Hood et al., 2018; Shapiro et al., 2021) that used data from the Supporting Teen Problem Solving (STePS) study randomized controlled trial (RCT). Hood et al. (2018) reported 1-year outcomes from the STePS study: interventions lasted 4.5 months, and assessments were conducted at baseline and 4.5, 8, 12, and 16 months (Hood et al., 2018). In the study by Shapiro et al. (2021), data were collected at seven time points over 3 years and analyzed using latent profile analysis and latent growth curve modeling (Shapiro et al., 2021).

Quantitative descriptive studies included 19 studies (Chambers et al., 2022; Demirtaş et al., 2022; Hilliard, Hagger, et al., 2017; Hilliard, Iturralde, et al., 2017; Huston et al., 2016; Jaser & White, 2011; Lo et al., 2016; Lord et al., 2015; Lukács et al., 2018; Luo et al., 2019; Perfect & Jaramillo, 2012; Scott et al., 2022; Sivertsen et al., 2014; Vesco et al., 2018; Weissberg-Benchell et al., 2016; Winsett et al., 2010; Xu et al., 2020; Yi-Frazier et al., 2015; Yi-Frazier et al., 2018). Out of those, there were 7 *cross-sectional* studies (Hilliard, Hagger, et al., 2017; Hilliard, Iturralde, et al., 2017; Huston et al., 2016; Jaser & White, 2011; Lo et al., 2016; Vesco et al., 2018; Yi-Frazier et al., 2015) and one longitudinal study (Yi-Frazier et al., 2018). One was a descriptive, methodological study of instrument translation and validation (Demirtaş et al., 2022), and two were prospective, observational studies (Lord et al., 2015; Xu et al., 2020). One of each was a follow-up analysis (Scott et al., 2022), a descriptive comparative pilot study (Winsett et al., 2010), a multicenter quantitative correlational design study (Lukács et al., 2018), a population-based study (Sivertsen et al., 2014), a survey with a convenience sample (Luo et al., 2019), and a nonblinded pilot study (Chambers et al., 2022).

Two studies (Hayes et al., 2017; Walker et al., 2015) were *mixed methods studies*. Hayes et al. (2017) used a sequential explanatory strategy: three quantitative measures were used individually or in small group sessions, and a semi-structured interview schedule was developed (Hayes et al., 2017). Walker et al. (2015) had an exploratory study: a parent/guardian survey and a separate survey for youths that involved taking five pictures with a provided disposable camera of "what diabetes means to you" (Walker et al., 2015).

Six different resilience instruments were found in the quantitative studies (n = 19) (Table 2). The Diabetes Strengths and Resilience Measure for adolescents (DSTAR-Teen) was used in eight studies (Chambers et al., 2022; Hilliard, Hagger, et al., 2017; Hilliard, Iturralde, et al., 2017; Hood et al., 2018; Luo et al., 2019; Vesco et al., 2018; Weissberg-Benchell et al., 2016; Xu et al., 2020), the Resiliency Scales for Children and Adolescents (RSCA) in four studies (Hayes et al., 2017; Hilliard, Iturralde, et al., 2017; Hood et al., 2018; Weissberg-Benchell et al., 2016), the Connor-Davidson Resilience Scale (CD-RISC-10) was used in two studies (Scott et al., 2022; Yi-Frazier et al., 2018), and as well as the Resilience Scale (RS) was used in two studies (Lukács et al., 2018; Winsett et al., 2010). The Adolescent Resilience Scale (ARS) was used in one study (Lo et al., 2016) and the Resilience Scale for Adolescents (READ) in one study (Sivertsen et al., 2014).

All the instruments are for patients' self-assessed perceptions of their own resilience. One instrument (DSTAR-Teen) is disease-specific and measures resilience in adolescents with T1D, three instruments (RSCA, ARS and READ) measure resilience in adolescents and two (RS and CD-RISC-10) are also used in adults. The instruments have mostly 10–15 items except for RSCA with 64 items consisting of three scales and READ with 28 items. All instruments use a Likert scale: one instrument (RS) has a 7-point Likert scale from one (strongly disagree) to seven (strongly agree) and the other five instruments have a 5-point Likert scale from one (strongly disagree) to five (strongly agree) or from zero (never) to four (almost always) (Table 2).

Reliability in terms of Cronbach's alpha was reported in most studies (see Table 2) and ranged from 0.78 to 0.90 for the DSTAR-teen, 0.90 for the Adolescent Resilience Scale, 0.83 for the Connor-Davidson Resilience Scale, 0.97 for the Resiliency Scales for Children and Adolescents, 0.95 for the Resilience Scale for Adolescents and 0.87 for the Resilience

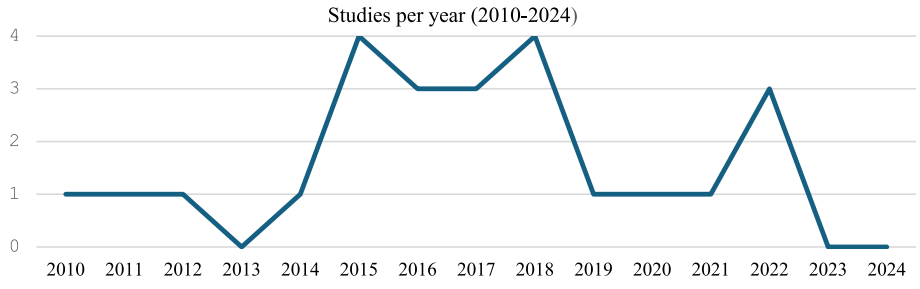

Fig. 2. Studies (*n* = 24) published in 2010–2024.

Scale, indicating high internal consistency of the instruments. Test-retest reliability was reported in one study using the DSTAR-teen (Xu et al., 2020) and one study using the RSCA (Hayes et al., 2017). Validity was not reported except for construct validity as a factor analysis in one study using the Adolescent Resilience Scale (Lo et al., 2016).

Discussion

This review shows that the use of the concept of resilience in studies of adolescents with T1D is relatively new, with all studies published in recent years (2010—2022). Most of the studies (15/24, 59%) were conducted in North America, with only four (17%) of the studies conducted in Europe, one (4%) in Australia and one (4%) in South America. More research is needed in Europe, especially in Nordic countries such as Finland and Sweden, where the incidence of adolescents with T1D is the highest in the world.

This review highlighted the need to have a clear definition and rationales for using the chosen concept of resilience. The definition of resilience or diabetes resilience was found in 18 out of 24 (75%) studies. The definition of resilience varied across the studies. Not all authors defined the concept, which can be problematic, because the use of the concept is not clear. These findings support the view of Morse et al. (2021) that there is no scientific agreement on the definition of resilience. Explicit definitions and conceptualization of resilience would make studies more comparable (Vella & Pai, 2019). The term "resilience" should be used for the process or phenomenon of competence in the face of adversity. One study used the term "resiliency," which should only be used when referring to a specific personality trait (Luthar et al., 2000).

One-half of the studies that included the definition (9/18, 50%) defined resilience as *the ability* or *capacity* to maintain physical and psychological well-being, despite exposure to significant stressors or distress events, or to recognize personal strengths. Although definitions of resilience vary between researchers, resilience is commonly related to adversity and positive outcomes: an individual facing adversity has the ability to bounce back or overcome and then experience positive outcomes despite the adversity (Vella & Pai, 2019).

Resilience training, particularly that based on mindfulness and/or training of cognitive and behavioral skills, can improve resilience (Joyce et al., 2018). Resilience-promoting interventions in adolescents with diabetes are promising in disease management and can improve glycated hemoglobin (HbA1c), stress, self-efficacy, and quality of life (Wu et al., 2023).

Resilience was also defined as *a process* (4/18, 22%). Resilience is seen as a process that involves positive adaptation to significant adversity, trauma, or tragedy – such as serious health problems or problems with family and relationships – especially through mental, emotional, and behavioral flexibility (American Psychological Association, 2023; Luthar et al., 2000). Resilience is seen as a dynamic process and is context-specific. An individual may be resilient in one context but not in another. Resilience occurs on a continuum: an individual may demonstrate different levels of resilience in different contexts (Vella & Pai, 2019).

Resilience as *a protective resource* (1/18, 6%) reflects the perceived ability to use the resources necessary for health. At the time of T1D diagnosis, resilience is particularly protective for adolescents. Stress-reducing and resilience-promoting interventions may improve long-term outcomes in adolescents with T1D (Yi-Frazier et al., 2018).

Two studies defined resilience very broadly (2/18, 11%) as consisting of four constructs: a sense of hopefulness, an optimistic explanatory style, effective coping strategies, and positive problem-solving skills due to the complex construct of resilience. When resilience is defined so broadly, it can be difficult to operationalize the concept.

Four studies had a diabetes-specific definition of resilience: *diabetes resilience* was defined as *achieving* of positive psychosocial and health outcomes despite the many challenges of living with T1D in adolescence (4/18, 22%). The diabetes-specific definition is needed to understand the importance of and different elements of resilience in adolescents with T1D and can be used in research.

In the future, it would be useful to carry out a more precise concept analysis of resilience in adolescents with T1D. It would be important to identify all uses of the concept, defining attributes and antecedents and consequences. This would help patients, nurses, and other health care professional to communicate and understand each other better.

The studies included in this review were mainly quantitative, with only one qualitative study and two mixed method studies. Surprisingly, there were few qualitative studies on resilience in adolescents with T1D. It appears that T1D researchers are using operationalizations of resilience that have been developed in contexts other than diabetes research. More interpretative studies of resilience in young people with T1D are needed.

In the quantitative studies, resilience was measured using six different resilience instruments: four (ARS, DSTAR-Teen, RSCA, READ) were for adolescents only; two (CD-RISC-10, RS) have also been used in adults. DSTAR-Teen was the most used instrument in the studies and the only instrument specifically geared to adolescents with T1D. It was developed based on the observational and interventional behavioral diabetes literature and resilience theory literature, clinical psychological experience and existing measures of related constructs, such as general resilience and diabetes-specific risk factors (Hilliard, Iturralde, et al., 2017).

The DSTAR-Teen was reported to be a reliable instrument in different studies, with Cronbach's alpha ranging from 0.78 to 0.90, indicating good reliability. ARS ($\alpha = 0.90$), CD-RISC-10 ($\alpha = 0.83$) and RS ($\alpha = 0.87$) were also reliable instruments according to Cronbach's alpha. The longest instruments, such as RSCA with 44 items, had a high alpha of 0.97 (usually 64 items; Hilliard, Iturralde, et al., 2017, used only two of the three scales of RSCA), and READ with 28 items also had a high alpha of 0.95 (>0.90) suggesting that redundancies and test length should be shortened (Tavakol & Dennick, 2011). This review did not provide a complete picture of the psychometric properties of the instruments, because the psychometric properties were not properly reported in the included studies. Test-retest reliability was reported in only one study using the DSTAR-Teen (Xu et al., 2020) and in one study using the RSCA (Hayes et al., 2017). Validity was not reported except for construct validity as a factor analysis in one study using the ARS (Lo et al., 2016). According to Ahern, Kiehl, Lou Sole, & Byers (2006), the RS was reported to be the most appropriate resilience instrument for adolescents based on its psychometric properties, but the review was conducted almost two decades ago and only three instruments (RS, ARS, CD-RISC) from this study were included in the review, so this finding should be treated with caution. There is a need for further investigation of the psychometric properties of resilience instruments in adolescents with T1D.

Limitations

This review has some limitations. Studies were excluded if the median age of the adolescents was not between 13 and 18 years, or if at least half of the participants were not in this age group. We may have lost some important information from excluded studies. We could have gotten more information from gray literature. An inclusion criterion was English language articles, and we may have missed some relevant information from non-English language studies (e.g., one study in Chinese).

In this review, the psychometric properties of the instruments were only reported according to the included studies, and not all studies provided all essential information on reliability and validity. A further methodological review would be needed to provide a consistent understanding of the reliability and validity of resilience instruments in adolescents with T1D.

Conclusions

Based on this integrative review, resilience in adolescents with T1D was defined as either an ability or capacity, or a process to maintain physical or psychological well-being despite exposure to significant stressors or distress events. Diabetes resilience was defined as achieving positive psychosocial and health outcomes despite the challenges of living with T1D. This review highlighted the need for an explicit definition of the concept, because studies used different definitions of resilience or lacked a definition. In most of studies, resilience in adolescents with T1D was defined as an ability or capacity, or a process to maintain physical or psychological well-being despite exposure to significant stressors or distress events. However, there were also other definitions or no definition at all. In the future, it would be useful conduct a systematic concept analysis of resilience in adolescents with T1D.

The results of this review indicate that the DSTAR-Teen is the most used and appropriate instrument in adolescents with T1D that could be used in future research. There is a need to conduct a review of the psychometric properties of resilience instruments in adolescents with T1D.

Implications for practice

The results of this review can be used to develop nursing interventions to promote resilience in adolescents with T1D. It would be important to involve adolescents in the planning of interventions how to promote resilience in adolescents with T1D. We recommend that researchers explicitly define the concept of resilience in every phase of the study. The DSTAR-Teen is a promising resilience measure that has been used in several studies, has good psychometric properties, and can be used in further studies in adolescents with T1D.

CRediT authorship contribution statement

Anne Survonen: Writing – review & editing, Writing – original draft, Visualization, Validation, Resources, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Riitta Suhonen:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Katja Joronen:** Writing – review & editing, Visualization, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization.

Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work the author used DeepL in order to improve language. After using this tool, the author reviewed and edited the content as needed and takes full responsibility for the content of the publication.

Declaration of competing interest

No conflicts of interest.

Acknowledgments

This work was supported by the Finnish Concordia Fund (2021), the State Research Fund/Turku University Hospital (2022) and the Finnish Nursing Education Foundation sr (2021).

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