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Socio-cognitive determinants affecting insulin adherence/non-adherence in late adolescents and young adults with type 1 diabetes: a systematic review

ABSTRACT

Non-adherence to insulin treatment is common in adolescents and young adults (AYAs) with type 1 diabetes (T1D) and is associated with increased morbidity and mortality. However, the socio-cognitive determinants (SCDs) of adherence in AYAs with T1D are less frequently represented in systematic reviews. This systematic review aimed to investigate the key SCDs associated with adherence/non-adherence to insulin treatment in AYAs in the age range of 17-24 years with T1D. A systematic review in PubMed, Embase, Web of Science, and PsycINFO was conducted. The search took place from 2021, to January 1st, 2022, and was repeated on June 5-7, 2022 and from July 18 to July 24, 2023. The methodological quality of studies was assessed by the National Heart, Lung, and Blood Institute quality assessment tool for observational cohort and cross-sectional studies. Six articles representing 973 AYAs with T1D were included for data extraction. The identified SCDs included risk perceptions, attitude, family and friends' social support, self-efficacy, and information factors. However, there was inconsistency in correlational findings among studies. The identified SCDs influencing insulin adherence in AYAs with T1D could serve as targets for patients' consultations and tailored interventions to improve adherence and overall health outcomes, as well as for policymakers to integrate these interventions into diabetes care planning. However, further research in the area of factors affecting insulin adherence in quality-designed studies that use detailed and comprehensive measures for assessing adherence is needed.

KEY WORDS

systematic review; type 1 diabetes; socio-cognitive determinants; insulin adherence and non-adherence; adolescents and young adults

BACKGROUND

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The prevalence of type 1 diabetes (T1D) is rising globally at a rate of 2-5% every three to six years (Shahbazi et al., 2018). Compared to other age groups, adolescents and young adults (AYAs) had the poorest control of their glucose levels when using insulin therapy (Miller et al., 2015). Adherence to insulin, defined as administering the correct dose at the right time and/or frequency in accordance with a mutually agreed-upon treatment regimen, is low in AYAs with T1D, ranging from 23% to 77%, with a higher rate in developing countries (Almeda-Valdes et al., 2020). Adhering to insulin therapy can be difficult for AYAs for a number of reasons, such as complex treatment regimens, psychological problems, physiological hormonal changes, family dynamics, and increasing independence (Helgeson, 2021). Non-adherence to insulin is associated with increased glycated hemoglobin (HbA1c) levels, diabetic ketoacidosis, increased hospitalization, and microvascular and macrovascular long-term complications which lead to increased morbidity and mortality (Borus & Laffel, 2010; Almeda-Valdes et al., 2020). Insulin non-adherence can be intentional or unintentional, and it includes situations in which AYAs did not fill their insulin prescriptions, reduced or omitted doses, or both (Borus & Laffel, 2010; Cramer, 2004; Doggrell & Chan, 2015).

Multiple factors affect insulin adherence (Chan et al., 2021; Cox & Hunt, 2015), including fixed factors such as socio-demographic factors (e.g., age, gender, ethnicity, personality, etc.) and socio-economic factors (e.g., cost of treatment) (Davies et al., 2013; Gloaguen et al., 2018; Gonzalez et al., 2016; Neylon et al., 2013). Other factors are either difficult to modify, such as certain psychosocial factors (e.g., diabetes emotional distress, depression, anxiety) (Berger et al., 2019; Gloaguen et al., 2018; Martinez et al., 2018; van Duinkerken et al., 2020) due to inadequate proper psychological and/or insurance support (Berger et al., 2019; Gloaguen et al., 2018; Martinez et al., 2018; van Duinkerken et al., 2020) or partly unmodifiable, such as medication regimen factors including the complexity of insulin regimen (Almeda-Valdes et al., 2020; Datye et al., 2015; Jaam et al., 2018), type of administration devices (Borus & Laffel, 2010; Davies et al., 2013; Gloaguen et al., 2018), and insulin side-effects (e.g., hypoglycemia). However, socio-cognitive factors are more likely to be modifiable (Cox & Hunt, 2015; Jaam et al., 2018; van Duinkerken et al., 2020) and can be targeted in interventions to improve adherence.

Overall, there is a gap in the systematic evidence that addresses various socio-cognitive determinants (SCDs) of insulin adherence among late adolescents and young adults with T1D. Previous systematic reviews that looked at socio-cognitive factors of insulin adherence among people with T1D mainly focused on adults (i.e., Davies et al., 2013; Gherman et al., 2011; Sigurdardóttir, 2005). The systematic/narrative reviews that did include adolescents and/or young adults did not exclusively relate to insulin adherence (investigated adherence to a range of diabetes self-management (DSM) behaviors including diet, physical activity, blood glucose monitoring and medication adherence) (i.e., Coyle et al., 2013; Martinez et al., 2018; Neylon et al., 2013) and/or did not exclusively relate to T1D (included people with either type 1 or type 2 diabetes) (i.e., Coyle et al., 2013; Gonzalez et al., 2016; Nagasawa et al., 1990; Robinson et al., 2021) and/or focused mainly on a few determinants (i.e., Datye et al., 2015; Neylon et al., 2013; Young et al., 2013). Hence, the relevance of these findings for AYAs with T1D is unclear. One narrative review (Datye et al., 2015) that specifically addressed insulin adherence in adolescents with T1D considered mainly psychological factors (e.g., mood, anxiety, and eating disorders), social support factors, and interactions with healthcare system factors.

Motivational factors are crucial in understanding whether a patient is aware of his/her current health situation and motivated to adhere to the prescribed medication, as well as for developing tailored patient education interventions (de Vries, 2017; Vluggen et al., 2020). Hence, it is important to systematically investigate all the socio-cognitive factors to identify which factors account for variations in adherence among AYAs with T1D, as this target group has received less attention. This review aimed to identify the key SCDs influencing adherence or non-adherence to insulin administration in late adolescents and young adults in the age range of 17-24 years with T1D. It was guided by a theoretical framework, the I-Change model (ICM; de Vries, 2017) (Figure 1), because the ICM integrates broader determinants of personal and environmental factors for the diagnosis of behavior. It distinguishes between pre-motivational factors (cognizance of one's behavior, knowledge, risk perceptions, and cues to action), motivational factors (attitude, social support, self-efficacy, and intention), post-motivational factors (action and coping planning), distal information factors, and preceding factors (e.g., personality, social-environmental context). The findings will be important to guide patients' consultations and diabetes self-management education (DSME) programs. They may also help to develop tailored insulin adherence improving interventions aimed at improving diabetes outcomes in people with T1D. The Population, Exposure, and Outcomes (PEO) strategy guided the development of the research question for this review to ensure a systematic search of available literature (Pollock & Berge, 2018). This review aims to identify the key SCDs influencing adherence or non-adherence to insulin administration in late adolescents and young adults in the age range of 17-24 years with T1D.

Figure 1

The I-Change model
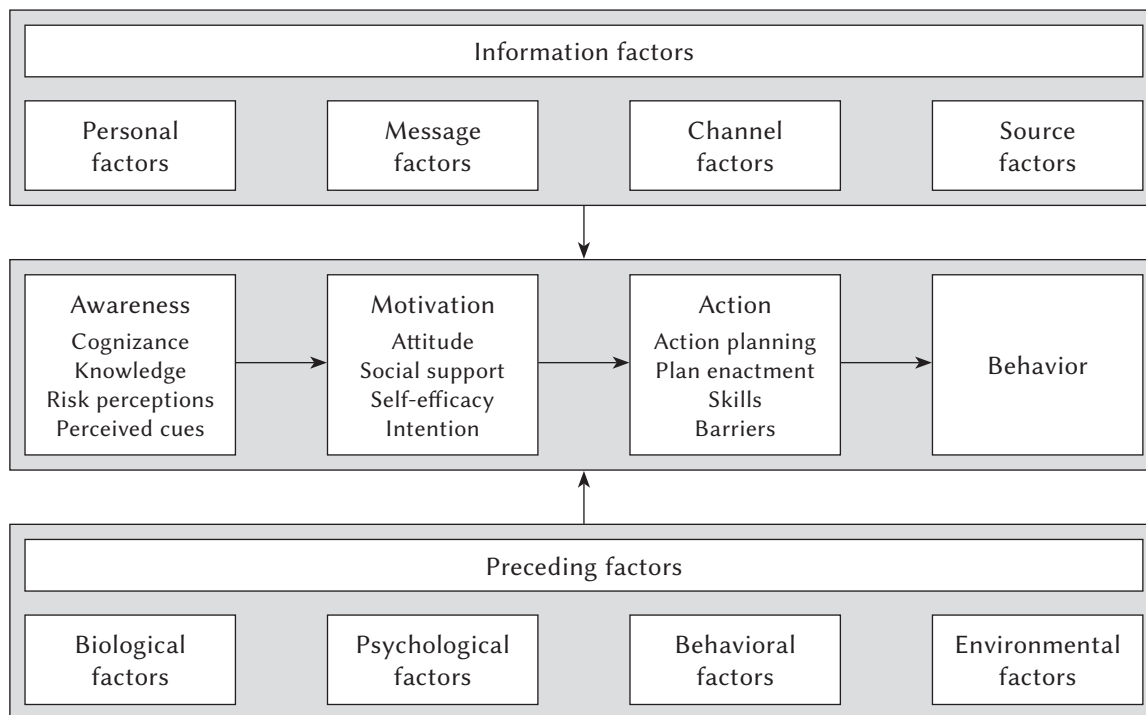
A systematic review on adherence in adolescents and young adults with T1D

Note. This figure has been reproduced with permission from de Vries (2017).

METHODS

AMENDMENT TO THE REGISTERED PROTOCOL

The study procedure followed the updated guidelines for reporting systematic reviews (PRISMA 2020; Page et al., 2021) and the published protocol for this review (AlBurno et al., 2022a). However, during the review process, the protocol registered with PROSPERO (ID: CRD42021233074) was amended to address changing the JBI Critical Appraisal Checklist for Cohort Studies and JBI Critical Appraisal Checklist for Analytical Cross-sectional Studies to the US National Heart, Lung, and Blood Institute (NHLBI) quality assessment tool for observational cohort and cross-sectional studies (The National Heart, Lung, and Blood Institute (NHLBI), 2021). Rather than using two separate checklists, we intended to use one tool that covers both cross-sectional and longitudinal study designs and has more aspects of critical appraisal that we deemed important.

ELIGIBILITY CRITERIA

The following criteria were used to include or exclude studies for this review:
1. Population: adolescents and/or young adults between the ages of 17 and 24 must be included in the study. The literature lacks a definitive definition for the young adult age range. However, our rationale for selecting this age group is grounded in studies from the National Institutes of Health (USA), which define young adulthood as ranging from 18 to 24 years (Institute of Medicine & National Research Council, 2015). Furthermore, research indicates that patients and families generally expect the transition to adult care to begin at age 17 (Iyengar et al., 2019), coinciding with the development of independence and appraisal skills. There were no restrictions on the gender or ethnicity of participants or the duration of diagnosis with T1D. Patients with a clinical diagnosis of comorbid conditions (e.g., depression, hypertension), people with cognitive impairments, drug or alcohol dependence, people who intentionally overdose for suicidal attempts, and pregnant women were excluded because each of these population groups has conditions that affect the nature of insulin adherence behavior.
2. Types of eligible studies: included peer-reviewed cohort studies with cross-sectional, longitudinal prospective, or retrospective cohort designs, published between 2000 and 2020, and written in English. A decision to identify studies only in the English language was made due to time and budget resource limits (Cooper et al., 2018; Lefebvre et al., 2022). The decision on publication years was made

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taking into account that the scope of this review is relatively broad in terms of the socio-cognitive factors of interest and because too narrow or too broad inclusion criteria can lead to an ineffective screening process (La Banca et al., 2020). The goal was to balance the thoroughness of searching published articles within a timeframe that is neither too narrow (to minimize bias resulting from missing articles) (Lefebvre et al., 2022) nor too wide (to stay abreast of the most recent evidence in the social sciences (Petticrew & Roberts, 2006) and advances in behavioral science related to T1D) (McSharry et al., 2020). Articles were excluded if they were randomized or non-randomized comparative studies of interventions. This is because it is expected that non-adherence will be lower than in the general population due to the controlled monitoring and administration of treatment in randomized trials (Davies et al., 2013); the interventional studies explicitly aim to influence outcomes (Dekkers et al., 2019); and they were included in previous reviews (i.e., O'Hara et al., 2017; Viana et al., 2016). Commentaries, letters, and editorials were also excluded.

3. Exposure variable(s): studies were selected if they investigated one or more of the SCDs associated with insulin adherence/non-adherence. ICM guided the selection of the primary exposures of interest. Therefore, studies reporting on patient motivation, awareness of behavior and illness perceptions, knowledge, risk perceptions, cues of action, attitudes, social influence, social norms, social modeling, self-efficacy, action planning, coping planning, information, self-regulation skills, and service-related factors were included in the review. Studies investigating factors other than SCDs, such as only socio-demographic and/or only psychological factors, were excluded. The reason for this is that these studies do not address the research question of interest. Besides, previous reviews (i.e., Gherman et al., 2011; Gloaguen et al., 2018) have provided evidence for them.

4. Outcome variable(s): studies which used adherence and/or non-adherence to insulin administration as an outcome and included details of the methods used to determine adherence were included. The secondary outcome was the quantified association between any measured SCD and adherence, if any. For more information about the outcome, see Appendix 3 in the extended data (AlBurno et al., 2022b).

DATA SOURCE AND SEARCH STRATEGIES

PubMed, Embase, Web of Science (WoS), and PsycINFO were searched using a predefined search strategy from October 15th, 2021, to January 1st, 2022. The emphasis was to complete study selection within approximately three months to ensure an up-to-date systematic review before future studies on the same topic are conducted to avoid bias in the reported results (Beller et al., 2013). We also aimed to achieve an optimal combination of databases to avoid missing relevant references (Bramer et al., 2017). A search strategy combining MeSH and EMTREE terms in PubMed and Embase and free-text words (including term explosion) in the titles and abstracts was used (Aromataris & Riitano, 2014; Li et al., 2019). Using the guideline for Peer Review of Electronic Search Strategies (PRESS; McGowan et al., 2016), SJ reviewed the list of systematically formulated search strings that included four index terms – (1) population, (2) exposure, (3) outcomes, and (4) study design – and any necessary adjustments were made before running the search. The PubMed search strategy is available as extended data (Appendix 1; AlBurno et al., 2022b). In WoS and PsycINFO, the thesaurus search terms (or subject headings) were used in keywords, titles, and abstract fields and combined with OR to improve the search. We did not filter specifically by age group; instead, our search strategy included studies on adolescents and/or young adults, or equivalent populations (see Appendix 1 in the data set; AlBurno et al., 2022b). Studies that covered our target age group along with a broader range, including both children and/or adults, were only included if separate analyses were conducted for the relevant age group. However, studies focusing exclusively on children and/or older adults were excluded based on titles and abstracts. In cases of uncertainty, the full article was read for a final decision.

Reference lists and citations from published studies and relevant reviews were reviewed for additional papers not indexed in the databases searched, and when necessary, corresponding authors were contacted for additional information (Horsley et al., 2011). Further, before submitting the systematic review for publication, the search was repeated on June 5, 2022, until June 7, 2022, in the original databases and using the original search strategy. The updated search included articles published between 2021 and 2022, apart from WoS, which allowed searching for articles published during the past three years, with one year overlap with the original search. This is to ensure that this systematic review is kept up to date by incorporating evidence from the most recently published articles (Bramer et al., 2017; Rethlefsen et al., 2021). Additionally, WoS email alerts were used to keep track of newly added references on the topic.

STUDY SCREENING AND SELECTION PROCEDURES

Firstly, duplicate records were removed electronically in Endnote X9 following the method described

by Bramer and colleagues (2016). Secondly, two researchers (HB and FS), working independently to minimize bias, screened the titles and then the abstracts for relevance. Thirdly, they screened the full articles for eligibility. Finally, they read and critically appraised the full text of each included study. If there was any uncertainty about study selection, the full article was read (Porritt et al., 2014). Disagreements on study eligibility were resolved by discussion with LM. The study selection process is shown in Figure 2.

ASSESSMENT OF METHODOLOGICAL QUALITY AND RISK OF BIAS

Two separate reviewers (HB and LM) assessed the quality of the included studies using the NHLBI quality assessment tool (NHLBI, 2021). A third reviewer (FS) resolved any disagreement. This tool can be used to rigorously appraise the quality of observational studies by determining the extent to which a study has addressed the possibility of bias in its design, conduct, and analysis. The quality assessment tool is depicted in Appendix 2 (extended data; AlBurno et al., 2022b). The overall quality and risk of bias were determined based on NHLBI (2021) guidelines. The number of positive answers to the 14 questions led to the final score of the study. The grading scores for the classification of the studies were good (≥ 11), fair (6-10), and poor (< 6). The quality assessment was used to discuss the studies' validity and not to exclude them from the review.

DATA EXTRACTION

A population, exposure, outcomes, and study characteristics framework was used to extract data. Two reviewers independently extracted data (HB and FS), and a third independent reviewer (LM) resolved disagreements in data extraction until a consensus was reached. Data were extracted using a standardized and piloted extraction form adapted from the Cochrane Public Health Group Data Extraction and Assessment Template (Higgins & Green, 2008). The following three types of data were extracted from selected studies: a) study data, b) outcome data, and c) study quality. Study data included: 1) publication, 2) population, 3) study characteristics, 4) exposure, and 5) results and findings. Outcome data were related to primary and secondary outcomes (see Appendix 3 in the extended data; AlBurno et al., 2022b).

DATA SYNTHESIS

A quantitative analysis was not statistically feasible due to the heterogeneity across studies because of the variety of SCDs used in eligibility criteria and/or methods used to measure insulin adherence. Hence, a qualitative narrative synthesis was performed and summarized in tables of findings, which present the characteristics and the outcomes of concern.

RESULTS

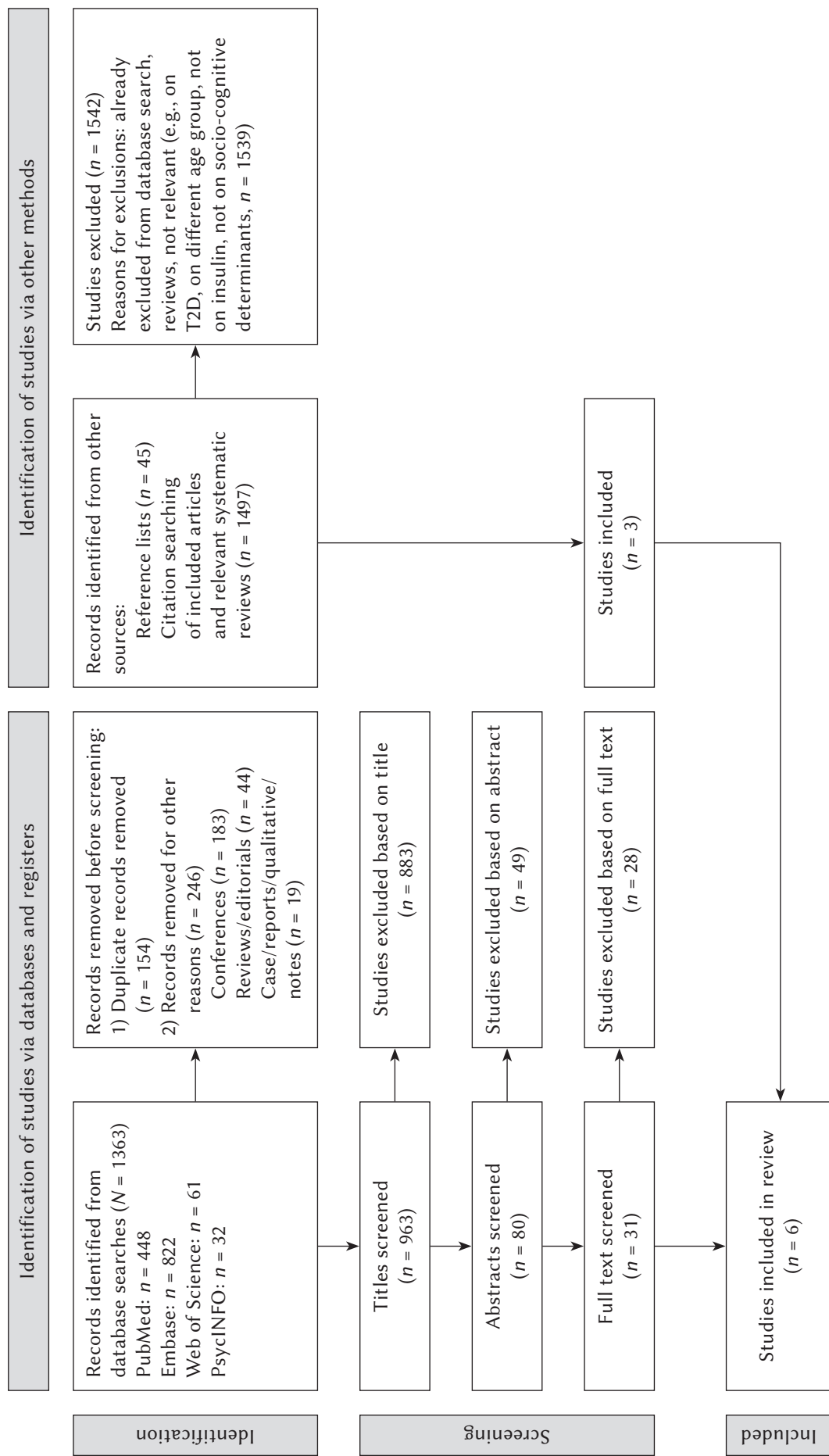### STUDY AND PARTICIPANT CHARACTERISTICS

A total of 6 articles (Farsaei et al., 2014; Griva et al., 2000; Riaz et al., 2014; Skinner et al., 2000, 2002; Skinner & Hampson, 2001) were considered eligible for the review from the original search (Figure 2). Three articles (Farsaei et al., 2014; Griva et al., 2000; Riaz et al., 2014) were found through database searches, and three others (Skinner et al., 2000, 2002; Skinner & Hampson, 2001) were found through screening reference lists and citations of published studies and relevant systematic reviews (see Appendix 4 in the extended data; AlBurno et al., 2022b). The repeated search yielded no additional articles from the total of 127 retrieved (PubMed = 65, Embase = 56, WoS = 127, PsycINFO = 22). Studies that were excluded from the initial and repeated searches did not meet the inclusion criteria because they addressed children and/or early adolescents or adults, involved people with either T1D or T2D without distinguishing between the two types in the analysis, examined overall DSM adherence, assessed the association between adherence or SCDs and metabolic control, tested psychometric properties of adherence measures, or were prevalence or interventional studies, as shown in Figure 2.

Of the included studies, four studies had a cross-sectional design and two a longitudinal design with measures after six months and one year. The population of these included studies represented 973 AYAs with T1D, and the sample size ranged from 52 to 358 patients. Various questionnaires for assessing SCDs were described. Four studies (Griva et al., 2000; Skinner et al., 2000, 2002; Skinner & Hampson, 2001) used validated and reliable questionnaires to measure pre-defined, specific socio-cognitive constructs based on theoretical frameworks. The theoretical models included Leventhal's Self-Regulatory Model (SRM) to measure diabetes perception beliefs (Griva et al., 2000; Skinner et al., 2000, 2002; Skinner & Hampson, 2001); self-efficacy, developed within the framework of social learning theory by Bandura (1977) (Griva et al., 2000), and social support theory (Skinner et al., 2000). Farsaei et al. (2014) and Riaz et al. (2014) developed their questionnaires to identify a set of factors influencing non-adherence, which were not based on a theoretical framework, although Farsaei et al. (2014) tested the validity and reliability of the questionnaire in their study.

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Figure 2

Flow diagram of included studies based on PRISMA statement (Page et al., 2021)

Identification of studies via databases and registers | Identification of studies via other methods

Identification

Records identified from database searches (*N* = 1363)
PubMed: *n* = 448
Embase: *n* = 822
Web of Science: *n* = 61
PsycINFO: *n* = 32

Records removed before screening:
1) Duplicate records removed (*n* = 154)
2) Records removed for other reasons (*n* = 246)
Conferences (*n* = 183)
Reviews/editorials (*n* = 44)
Case/reports/qualitative/notes (*n* = 19)

Records identified from other sources:
Reference lists (*n* = 45)
Citation searching of included articles and relevant systematic reviews (*n* = 1497)

Studies excluded (*n* = 1542)
Reasons for exclusions: already excluded from database search, reviews, not relevant (e.g., on T2D, on different age group, not on insulin, not on socio-cognitive determinants, *n* = 1539)

Screening

Titles screened (*n* = 963)

Studies excluded based on title (*n* = 883)

Abstracts screened (*n* = 80)

Studies excluded based on abstract (*n* = 49)

Full text screened (*n* = 31)

Studies excluded based on full text (*n* = 28)

Included

Studies included (*n* = 3)

Studies included in review (*n* = 6)

Five studies (Griva et al., 2000; Riaz et al., 2014; Skinner et al., 2000, 2002; Skinner & Hampson, 2001) investigated multiple DSM adherence behaviors and were included because the analysis for insulin was performed separately. Three of them (Skinner et al., 2000, 2002; Skinner & Hampson, 2001) used the Summary of Diabetes Self-Care Schedule (SDSS). The SDSS used two items to measure the frequency and timing of insulin injections in the past 7 days, and the items were treated as an ordinal scale (no cut-off point was used for adherence and non-adherence). The other two studies (Griva et al., 2000; Riaz et al., 2014) used a self-developed questionnaire and used a dichotomous adherence classification with different cut-off points: poor vs. good adherers (Griva et al., 2000) or adherents vs. non-adherents (Riaz et al., 2014). The sixth study used two specific insulin adherence measures: the 8-Item Morisky Medication Adherence Scale (MMS-8), which used the questionnaire's cut-off points to classify adherence into three categories – low, medium, and high; and the auto-compliance method (Farsaei et al., 2014), where patients were considered compliant with insulin if they reported taking > 80% of the total number of prescribed insulin injections. Evidence of validity and reliability of adherence questionnaires was reported in four studies (Griva et al., 2000; Skinner et al., 2000, 2002; Skinner & Hampson, 2001). The study characteristics are described in Table 1.

DETERMINANTS OF ADHERENCE OUTCOMES

The ICM offers a socio-cognitive framework for understanding health behavior. Hence, the identified determinants were grouped into distinct phases following the ICM framework to allow for a holistic approach to identify the determinants influencing adherence that could be targeted in more effective tailored interventions towards optimizing insulin adherence.

PRE-MOTIVATIONAL FACTORS: RISK PERCEPTIONS

The determinants identified within the pre-motivational phase were risk perceptions (the perceived consequences of diabetes, consisting of the perceived seriousness (threat) of diabetes; and the perceived impact of diabetes) (Griva et al., 2000; Skinner et al., 2000, 2002; Skinner & Hampson, 2001), and the results in relation to insulin adherence were mixed. In a cross-sectional study (Skinner et al., 2002), the perceived threat of diabetes was associated with adherence but not the perceived impact. The perceived seriousness (threat) of diabetes and the perceived impact of diabetes were not associated with adherence in more than one study when investigated cross-sectionally (Griva et al., 2000) or prospectively (Skinner et al., 2000; Skinner & Hampson, 2001).

MOTIVATIONAL FACTORS: ATTITUDE, SOCIAL SUPPORT, AND SELF-EFFICACY

The motivational determinants included (1) attitude; perceptions about the advantages and the disadvantages of insulin adherence (Farsaei et al., 2014; Riaz et al., 2014), the perceived treatment effectiveness to control diabetes and the perceived treatment effectiveness to prevent complications (Skinner et al., 2000, 2002; Skinner & Hampson, 2001), (2) social support from family and friends (Skinner et al., 2000), and (3) self-efficacy, conceptualized as control beliefs (personal beliefs that the patient can control and manage diabetes) (Griva et al., 2000), as well as generalized and diabetes-specific self-efficacy, conceptualized as situations in which patients find it difficult to perform the behavior under challenging situations (Griva et al., 2000) or defined as barriers to adherence (Farsaei et al., 2014; Riaz et al., 2014). Five studies investigated attitude (Farsaei et al., 2014; Riaz et al., 2014; Skinner et al., 2000, 2002; Skinner & Hampson, 2001), and the results were mixed. There was a positive correlation between the perceived benefits for controlling diabetes and preventing complications ($p < .005$) in one cross-sectional study (Skinner et al., 2002) but not in two prospective studies (Skinner et al., 2000; Skinner & Hampson, 2001). A significant association was also found between insulin non-adherence and negative attitudes (e.g., reported disadvantages of using insulin such as being time-consuming, weight gain, feeling worse after injections, experience of hypoglycemia (Farsaei et al., 2014), and medication cost (Farsaei et al., 2014). Other attitude factors, such as interference with usual daily activities, interference with meal planning, interference with physical activities, injection site pain, injection site reactions, and belief that insulin has a negative effect on overall health, were not found to be predictive of adherence (Farsaei et al., 2014). One study (Skinner et al., 2000) investigated social support factors from family or friends and they were not found to be potential predictors for adherence. Three studies examined self-efficacy (Farsaei et al., 2014; Griva et al., 2000; Riaz et al., 2014), and the results were inconsistent. Control beliefs showed a positive moderate correlation with adherence ($r = .41$, $p < .001$) (Griva et al., 2000). A significant correlation was found between non-adherence to insulin and some difficult situations, such as feeling embarrassed by insulin injections, finding it difficult to prepare injections, forgetfulness, insulin shortages, and sick days (Farsaei et al., 2014). There was no association between insulin adherence and generalized and diabetes-specific self-efficacy (Griva et al., 2000), injection difficulties, inability to self-inject (Farsaei et al., 2014), or embarrassment with insulin injections (Riaz et al., 2014).

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Table 1

Characteristics of studies included in the systematic review

Author, year (country)	Study design and setting	Purpose	Sample description (sample size, mean age (*SD*)*, gender, ethnicity, average duration of diabetes in years, insulin device, and average number of daily injections)	Socio-cognitive determinants (SCDs) measured (the I-change construct), tools used to measure SCDs and the internal reliability of measure (Cronbach's α coefficient)	Adherence measurement and internal reliability of measure	Analysis used, significance level (*p*), studied cofounders [*r, p, t*]*
Griva et al., 2000 (UK)	*Design:* cross-sectional *Setting:* diabetes care clinics at two university-affiliated hospitals	To investigate the relationship between illness perceptions and self-efficacy expectancies and to examine their respective and combined role in explaining treatment adherence and metabolic control in young patients with insulin-dependent diabetes	*Sample size:* 64 (26 adolescents and 38 adults) *Mean age:* 20.6 (*SD* = 3.28) *Gender:* 48% male *Ethnicity:* 100% Caucasian *Average duration of diabetes in years:* 7.91 (*SD* = 4.67) *Insulin devices:* pre-mixed insulin injections pens *Average number of daily injections:* – 4 injections: 68.6% – 3 injections: 18.3% – 2 injections: 14.1%	1. *Illness perceptions: consequences of diabetes (risk perceptions),* the diabetes version of Illness Perception Questionnaire (Weinman & Horne, 1994), 5-item, 5-point Likert scale, aggregate score range: 1–5, α = .79, and mean inter-item correlation = .36 2. *Illness perceptions: control/cure (self-efficacy),* the diabetes version of Illness Perception Questionnaire (Weinman & Horne, 1994), 5-item, 5-point Likert scale, aggregate score range: 1–5, α = .72, and mean inter-item correlation = .22 3. *Generalized self-efficacy (self-efficacy),* the English language version of the Generalized Self-Efficacy Scale (Jerusalem & Schwarzer, 1992; Schwarzer & Jerusalem, 1995), 10-item, 4-point Likert scale, aggregate score range: 10–40, α = .87, and mean inter-item correlation = .39 4. *Diabetes-specific self-efficacy (self-efficacy),* a modified version of the Self-Efficacy for Diabetes Scale originally developed by Grossman et al. (1987) and modified by Havermans & Eiser (1991), 22-item, 5-point Likert scale, aggregate scores ranging from 22 (*low efficacy*) to 110 (*high efficacy*)¶, ‡ The reliability and validity have been established (Anderson et al., 1985; Grossman & Brink, 1984; Starkman et al., 1984).	Constructed Adherence scale (based upon the Reported Adherence to Medication Scale, a supplementary subscale of the Beliefs about Medicines Questionnaire; Horne et al., 1999). It comprised 4 items assessing how often patients generally do not perform the four self-care behaviors (insulin administration, diet, blood glucose monitoring and exercise), as recommended by their doctor using a 5-point Likert scale ranging from *always/very often* to *never* with lower scores indicating intentional poor adherence. Patients were categorized into two categories: 1. "good adherers": if patients never or rarely deviated from treatment recommendations and 2. "intentional poor adherers": if patients sometimes, often, or always/very often deviated from treatment recommendations. α = .76, and inter-item correlations = .44	Bivariate Pearson product moment (*r*), at *p* < .01 to test the associations between insulin adherence and SCDs *T-test:* to test the associations between different levels of adherence (good, poor) with different beliefs at *p* < .01 Included cofounders: gender, age, duration of illness, age at onset, years of education and insulin regimen

Table 1 continues

Table 1

Table 1 continues

Author, year (country)	Study design and setting	Purpose	Sample description (sample size, mean age (SD)*, gender, ethnicity, average duration of diabetes in years, insulin device, and average number of daily injections)	Socio-cognitive determinants (SCDs) measured (the I-change construct), tools used to measure SCDs and the internal reliability of measure (Cronbach's α coefficient)	Adherence measurement and internal reliability of measure	Analysis used, significance level (p), studied cofounders [r, p, t]*
Skinner et al., 2000 (UK)	*Design:* longitudinal with 6-month follow-up *Setting:* four regional hospitals in the south of England	To examine whether peer support and illness representation mediate the link between family support, self-management, and well-being	*Sample size:* 52 *Mean age in years:* 15.6 (SD = 1.9) *Gender:* 54% male *Ethnicity**:* 82% Caucasian, 8% non-Caucasian *Average duration of diabetes in years:* 5.9 (SD = 3.6) *Insulin device:* not reported *Number of daily injections:* not reported	1. *Perceived seriousness of diabetes (risk perceptions),* the Personal Models of Diabetes Questionnaire, developed from the Personal Models of Diabetes Interview (Hampson et al., 1990, 1995), 2-item, 5-point Likert scale, α = .60 2. *Perceived impact of diabetes (risk perceptions),* the Personal Models of Diabetes Questionnaire, developed from the Personal Models of Diabetes Interview (Hampson et al., 1990, 1995), 2-item, 5-point Likert scale, α = .68 3. *Perceived effectiveness of treatment to control diabetes (attitude),* the Personal Models of Diabetes Questionnaire, developed from the Personal Models of Diabetes Interview (Hampson et al., 1990, 1995), 2-item, 5-point Likert scale, α = .71 4. *Perceived effectiveness of treatment to prevent complications (attitude),* the Personal Models of Diabetes Questionnaire, developed from the Personal Models of Diabetes Interview (Hampson et al., 1990, 1995), 2-item, 5-point Likert scale, α = .45 5. *General family support (social support),* the Perceived Social Support from Family Questionnaire (Procidano & Heller, 1983), 20-item "yes," "no," or "don't know" scale, α = .89 6. *General peer support (social support),* the Perceived Social Support from Friends Questionnaire (Procidano & Heller, 1983), a 20-item "yes," "no," or "don't know" scale, α = .86 7. *Diabetes-specific family support (social support),* a modified Diabetes Family Behavior Checklist (DFBC; Schafer et al., 1986), 12-item Likert scale, total support score = sum of multiplications of the frequency (using 5-point Likert scale) and helpfulness scores (using 7-point Likert scale), α = .83	The Summary of Diabetes Self-Care Schedule (Toobert & Glasgow, 1994). This is a validated 12-item self-reported instrument that assessed four areas of diabetes self-management (diet, exercise, blood glucose monitoring, and injecting) over the previous 7 days. 2 items measure the frequency and timing of insulin injections in the past 7 days. (Items were treated as an ordinal scale, no cut-off point was used for adherence and non-adherence)¶. α = .41	Bivariate analyses (using Pearson's product moment correlation co-efficient or Kendall's tau)¶ to test the associations between insulin adherence and SCDs Included cofounders: gender, age, duration of diabetes, and socioeconomic status

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Table 1 continues

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Table 1

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Author, year (country)	Study design and setting	Purpose	Sample description (sample size, mean age (SD)*, gender, ethnicity, average duration of diabetes in years, insulin device, and average number of daily injections)	Socio-cognitive determinants (SCDs) measured (the I-change construct), tools used to measure SCDs and the internal reliability of measure (Cronbach's α coefficient)	Adherence measurement and internal reliability of measure	Analysis used, significance level (*p*), studied cofounders [*r*, *p*, *t*]*
				8. *Diabetes-specific peer support (social support)*, Diabetes Inventory of Peer Support (DIPS), based on Skinner et al. (1999), which used Diabetes Social Support Interview (La Greca et al., 1995), 12-item Likert scale, total support score = sum of multiplications of the frequency (using 5-point Likert scale) and helpfulness scores (using 7-point Likert scale), α = .69		
Skinner & Hampson, 2001 (UK)	*Design:* longitudinal with 1-year follow-up *Setting:* four regional hospitals in southern England	To examine whether personal models of diabetes have any utility in predicting self-care, well-being, and glycemic control during adolescence	*Sample size:* 54 *Mean age in years:* 15.18 (*SD* = 2.01) *Gender:* 54% male *Ethnicity:* not reported *Average duration of diabetes in years[§]:* males, T1[§§]: 4.8 (*SD* = 3.0); females, T1: 5.0 (*SD* = 4.5) *Insulin device:* not reported *Number of daily injections[§]:* 2 injections: males: 86% females: 92% remaining 4 patients: not specified	1. *Perceived seriousness of diabetes (risk perceptions)*, the Personal Models of Diabetes Questionnaire developed from the Personal Models of Diabetes Interview (Hampson et al., 1990, 1995), 2-item, 5-point Likert scale, ranging from 1 (*not at all serious*) to 5 (*extremely serious*), internal consistency, *r* = .60 (Spearman's rho [ρ] correlation coefficient) 2. *Perceived impact of diabetes (risk perceptions)*, the Personal Models of Diabetes Questionnaire developed from the Personal Models of Diabetes Interview (Hampson et al., 1990, 1995), 2-item, 5-point Likert scale, ranging from 1 (*not at all likely to help*) to 5 (*extremely likely to help*), internal consistency, *r* = .68 (Spearman's rho [ρ] correlation coefficient) 3. *Perceived effectiveness of treatment to control diabetes (attitude)*, the Personal Models of Diabetes Questionnaire developed from the Personal Models of Diabetes Interview (Hampson et al., 1990, 1995), 2-item, 5-point Likert scale, ranging from 1 (*not at all important*) to 5 (*extremely important*), internal consistency *r* = .54 (Spearman's rho [ρ] correlation coefficient)	The Summary of Diabetes Self-Care Schedule (Toobert & Glasgow, 1994). This is a validated 12-item self-reported instrument that assesses four areas of diabetes self-management (diet, exercise, blood glucose monitoring, and injecting) over the previous 7 days. 2 items measure the frequency and timing of insulin injections in the past 7 days. (Items were treated as an ordinal scale, no cut-off point was used for adherence and non-adherence)[¶]. α = .41	Bivariate analyses (using Pearson's product moment correlation coefficient or Kendall's tau)[¶], between changes in diabetes personal beliefs (baseline means minus 12-month follow-up means) and changes in insulin adherence, at *p* < .01. Included cofounders: gender, age, duration of diabetes, and socio-economic status

Table 1 continues

Table 1

Table 1 continues

Author, year (country)	Study design and setting	Purpose	Sample description (sample size, mean age (SD)*, gender, ethnicity, average duration of diabetes in years, insulin device, and average number of daily injections)	Socio-cognitive determinants (SCDs) measured (the I-change construct), tools used to measure SCDs and the internal reliability of measure (Cronbach's α coefficient)	Adherence measurement and internal reliability of measure	Analysis used, significance level (p), studied cofounders [r, p, t]*
				4. *Perceived effectiveness of treatment to prevent complications (attitude)*, the Personal Models of Diabetes Questionnaire developed from the Personal Models of Diabetes Interview (Hampson et al., 1990, 1995), 2-item, 5-point Likert scale, ranging from 1 (*not at all likely to help*) to 5 (*extremely likely to help*), internal consistency, r = .48 (Spearman's rho [ρ] correlation coefficient)		
Skinner et al., 2002 (UK)	*Design:* cross-sectional *Setting:* British Diabetic Association for adolescents and young adults with diabetes registry (excluding members who were resident overseas)	To test the hypothesized associations among personality, personal models, and self-care in a sample of young adults and adolescents with type 1 diabetes	*Sample size:* 338 *Mean age in years*§: males: 22.2 (SD = 4.4), females: 21.8 (SD = 4.1) *Gender:* 28% males *Ethnicity:* Caucasian, others (not specified) *Average duration of diabetes in years*§: males: 10.7 (SD = 6.7); females: 10.6 (SD = 6.1) *Insulin device:* not reported *Number of daily injections:* – 2 injections: males: 32%, females: 35% – 4 injections: males: 61%, females: 58% – Other: males: 7%, females: 7%	1. *Perceived consequences of diabetes (risk perceptions)*, the Perceived Consequences scale, based on the Perceived Consequences of the Illness Perception Questionnaire (Weinman et al., 1996), the Personal Models of Diabetes Interview (Hampson et al., 1990, 1995), also on fear of hypoglycemia and threat of diabetes on health, 15-item, 5-point Likert scale, ranging from 1 (*strongly agree*) to 5 (*strongly disagree*), α = .78 2. *Perceived impact of diabetes (risk perceptions)*, included in the above perceived consequences of diabetes scale to measure the threat of diabetes on health, 2-items, 5-point Likert scale ranging from 1 (*strongly agree*) to 5 (*strongly disagree*), α = .80 3. *Perceived effectiveness of treatment to control diabetes (attitude)*, the Perceived Treatment Effectiveness to Control Diabetes, based on scales developed by Glasgow et al. (1997), 2-item on managing sick days, 5-point Likert scale ranging from 1 (*not important*) to 5 (*extremely important*), α = .74 4. *Perceived effectiveness of treatment to prevent the complications of diabetes (attitude)*, the Perceived Treatment Effectiveness to Prevent the Complications of Diabetes, based on scales developed by Glasgow et al. (1997), 2-item on managing sick days, 5-point Likert scale ranging from 1 (*not likely to help*) to 5 (*extremely likely to help*), α = .82	The Summary of Diabetes Self-Care Schedule (Toobert & Glasgow, 1994). This is a 12-item validated self-reported instrument that assesses four areas of diabetes self-management: diet (5 items), exercise (3 items), blood glucose monitoring (2 items), and the frequency and timing of insulin injections (2 items) over the previous 7 days; α = .57. (Items were treated as an ordinal scale, no cut-off point was used for adherence and non-adherence)¶. Responses to each item were standardized across the study sample, and the mean standardized scores for each scale were calculated	Bivariate analyses (using Pearson's product moment correlation coefficient or Kendall's tau)¶, to test the associations between insulin adherence and SCDs Included cofounders: gender, age, duration of illness, and socioeconomic status

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Author, year (country)	Study design and setting	Purpose	Sample description (sample size, mean age (SD)*, gender, ethnicity, average duration of diabetes in years, insulin device, and average number of daily injections)	Socio-cognitive determinants (SCDs) measured (the I-change construct), tools used to measure SCDs and the internal reliability of measure (Cronbach's α coefficient)	Adherence measurement and internal reliability of measure	Analysis used, significance level (*p*), studied cofounders [*r*, *p*, *t*]*
Farsaei et al., 2014 (Iran)	*Design:* cross-sectional *Setting:* outpatient diabetes clinic (Endocrinology and Metabolism Research Center – EMRC) affiliated to Tehran University of Medical Sciences (TUMS)	To evaluate adherence to insulin therapy in patients with diabetes. The secondary goal of the study was to investigate the underlying factors that may predispose patients to low insulin adherence	*Gender:* 51% male *Ethnicity:* not reported *Average duration of diabetes in years:* 8.3 (*SD* = 7.3) *Insulin device:* 90.8% syringe, 9.2% pen *Number of daily injections:* – 1 injection: 5.2% – 2 injections: 59.4% – 3 or more injections: 35.5%	1. *Time consuming (attitude)* 2. *Weight gain (attitude)* 3. *Feeling worse after insulin injection (attitude)* 4. *Experience of hypoglycemia (attitude)* 5. *Cost (attitude)* 6. *Interference with usual daily activities (attitude)* 7. *Interference with meal planning (attitude)* 8. *Interference with physical activities (attitude)* 9. *Injection site pain (attitude)* 10. *Injection site reactions (attitude)* 11. *Belief in negative effects of insulin on overall health (attitude)* 12. *Embarrassment (self-efficacy)* 13. *Difficulties in preparing injection (self-efficacy)* 14. *Forgetfulness (self-efficacy)* 15. *Insulin shortage (self-efficacy)* 16. *Sick days (self-efficacy)* 17. *Difficult to inject (self-efficacy)* 18. *Incapability for self-injection (self-efficacy)* 19. *Lack of enough injection instructions (information factors)*	1. 8-Item Morisky Medication Adherence Scale (MMAS-8), ¶(this scale consists of 8 items, the first 7 of which are yes/no questions, and the last of which is a 5-point Likert-scale rating). It categorizes patients into low, medium and high adherents if they received scores < 6.0, 6.0 – < 8.0 and 8 respectively. Internal validity and reliability: not reported 2. Autocompliance method: estimates the number of skipped insulin injections during the previous month, following the methodology of Haynes et al. It measures according to patient self-reporting of difficulty in taking the medication by asking two open questions: (1) "Did you have any difficulties in insulin injection?" and (2) "How many times did you skip insulin injection in the last month?" Autocompliance was calculated using the following formula: 100* total number of insulin injections / total number of prescribed insulin injections. The patient is considered adherent if he/she is taking more than 80% of the total number of prescribed insulin injections during the previous month	T-test for parametric variables and Mann-Whitney *U*-test for non-parametric variables, at *p* < .05 to test the association between level of adherence and SCDs Included cofounders: not reported

Table 1 continues

Table 1

Table 1 continues

Author, year (country)	Study design and setting	Purpose	Sample description (sample size, mean age (SD)*, gender, ethnicity, average duration of diabetes in years, insulin device, and average number of daily injections)	Socio-cognitive determinants (SCDs) measured (the I-change construct), tools used to measure SCDs and the internal reliability of measure (Cronbach's α coefficient)	Adherence measurement and internal reliability of measure	Analysis used, significance level (*p*), studied cofounders [*r, p, t*]*
Riaz et al., 2014 (Pakistan)	*Design:* cross-sectional *Setting:* a tertiary care diabetes unit (Baqai Institute of Diabetology & Endocrinology – BIDE), and a primary care diabetes center of Karachi (Diabetic Association of Pakistan – DAP)	To identify the various factors associated with non-adherence to diet, physical activity and insulin among patients with type 1 diabetes	*Sample size:* 194 *Mean age in years:* 17.9 (*SD* = 6.4) *Gender:* 49% male *Ethnicity:* 10.8% Punjabi, 16.5% Sindhi, 51% Muhajir, 21.6% Others (Balochis, Pashtuns, Memons) *Average duration of diabetes in years:* 5.37 (*SD* = 4.96) *Insulin device:* not reported *Number of daily injections:* not reported	Authors developed the questionnaire, which included the following factors (internal validity and reliability: not reported): 1. *Knowledge regarding diabetes (knowledge),* knowledge scores and level: scores < 40%, 40-60%, and > 60% were categorized as poor, moderate and good levels of knowledge respectively 2. *Cost (attitude)* 3. *Embarrassment of taking insulin (self-efficacy)* 4. *Frequency of visits to diabetic clinics and diabetes education (information factors)*	The authors developed the questionnaire. It categorized patients into two categories: 1. adherents: if patients scored 100% for the recommended drug advice, and 2. non-adherents: if patients scored < 100% for the recommended drug advice. *Internal reliability:* not reported	Independent *t*-test, at *p* ≤ .05: to test the association between level of adherence and SCDs One-way analysis of variance (ANOVA), at *p* < .05 to assess the significant difference between the groups followed by post hoc: Bonferroni test for multiple comparisons to find out which group was significantly different Included cofounders: not reported

Note. *[*SD* – standard deviation, *r* – Pearson correlation coefficient, *p* – significance level, *t* – *t*-test]; **information obtained from Skinner & Hampson, 1998; §total sample statistics were not reported, so only data on males and females were mentioned separately; §§T1 – baseline time; ¶the author was contacted and provided the information; ¶¶information obtained from Moon et al., 2017; ‡information obtained from Havermans & Eiser, 1991.

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Table 2

Overview of reported outcome measures by study

Author, year	Socio-cognitive determinants (SCDs) (the I-change construct) [M (SD), N (%)]*	Adherence/non-adherence [M (SD), z (SD), n (%)]*	Correlational results between SDCs and adherence/ non-adherence [r, p, t]*	Cofounder results [r, p, t, F, df]*
Griva et al., 2000	1. Illness perceptions: consequences of diabetes (risk perceptions): M = 3.33 (SD = 0.78) 2. Illness perceptions: control/cure (self-efficacy): M = 3.72 (SD = 0.51) 3. Generalized self-efficacy (self-efficacy): M = 30.16 (SD = 4.90) 4. Diabetes-specific self-efficacy (self-efficacy): M = 65.55 (SD = 15.18)	M = 13.20 (SD = 3.33)	A) Correlations with adherence: 1. Consequences of diabetes (risk perceptions), r = -.12 (not significant)** 2. Control/cure (self-efficacy), r = .41, p < .001 (significant) 3. Generalized self-efficacy (self-efficacy), r = .21 (not significant)** 4. Diabetes-specific self-efficacy (self-efficacy), r = -.25 (not significant)** B) Categorical analysis: between patients reporting good and poor adherence to insulin recommendations: 1. Consequences of diabetes (risk perceptions): (not significant)** 2. Control/cure (self-efficacy): t(62) = 2.79, p = .007 (significant) 3. Generalized self-efficacy (self-efficacy): (not significant)** 4. Diabetes-specific self-efficacy (self-efficacy): (not significant)**	T-test comparisons between males and females and between adults and adolescents revealed no significant differences, and thus all subsequent analyses were conducted on the combined sample. Duration of illness, age at onset, years of education and insulin regimen were not significantly correlated with the independent and dependent measures
Skinner et al., 2000	1. Illness perceptions: perceived seriousness of diabetes (risk perceptions): males: M = 5.67 (SD = 1.7), females: M = 7.00 (SD = 2.0) 2. Illness perceptions: perceived impact of diabetes (risk perceptions): males: M = 4.59 (SD = 1.9), females: M = 6.05 (SD = 2.15) 3. Illness perceptions: perceived effectiveness of treatment to control diabetes (attitude): males: M = 7.04 (SD = 1.8), females: M = 7.5 (SD = 1.3) 4. Illness perceptions: perceived effectiveness of treatment to prevent complications (attitude): males: M = 7.67 (SD = 1.3), females: M = 7.64 (SD = 1.4) 5. General family support (social support): males: M = 9.79 (SD = 4.7), females: M = 8.74 (SD = 5.4) 6. General peer support (social support): males: M = 11.00 (SD = 4.1), females: M = 13.22 (SD = 5.2) 7. Diabetes-specific family support (social support): males: M = 23.26 (SD = 24.5), females: M = 19.5 (SD = 25.0) 8. Diabetes-specific peer support (social support): males: M = 17.19 (SD = 18.4), females: M = 20.05 (SD = 17.85)	Males: M = 5.64 (SD = 0.8), Females: M = 4.95 (SD = 1.3)	Correlations with adherence: 1. Perceived seriousness of diabetes (risk perceptions): (not significant)** 2. Perceived impact of diabetes (risk perceptions): (not significant)** 3. Perceived effectiveness of treatment to control diabetes (attitude): (not significant)** 4. Perceived effectiveness of treatment to prevent complications (attitude): (not significant)** 5. General family support (social support): (not significant)** 6. General peer support (social support): (not significant)** 7. Diabetes-specific family support (social support): (not significant)** 8. Diabetes-specific peer support (social support): (not significant)**	There were no significant correlations between demographic characteristics and change scores, but there were a number of gender differences. Girls reported a greater decrease in family support both generally (t(49)) = 2.08, p < .05) and for diabetes-specific family support (t(49) = 2.52, p < .02) than boys. In addition, girls' injecting behavior got worse over the 6-month follow-up, whereas the boys' injecting behavior improved slightly (t(50) = 2.85, p < .004), and this effect remained when controlling for age, duration, and injecting behavior at time of recruitment. Age, duration of diabetes, and socioeconomic status were not significantly correlated with the independent and dependent measures

Table 2 continues

Table 2

Table 2 continues

Author, year	Socio-cognitive determinants (SCDs) (the I-change construct) [M (SD), N (%)]*	Adherence/non-adherence [M (SD), z (SD), N (%)]*	Correlational results between SDCs and adherence/non-adherence [r, p, t]*	Cofounder results [r, p, t, F, df]*
Skinner & Hampson, 2001	1. *Illness perceptions: perceived seriousness of diabetes (risk perceptions):* males: M = 6.0 (SD = 1.7), females: M = 7.2 (SD = 1.7) 2. *Illness perceptions: perceived impact of diabetes (risk perceptions):* males: M = 4.2 (SD = 2.2), females: M = 5.3 (SD = 1.6) 3. *Illness perceptions: perceived effectiveness of treatment to control diabetes (attitude):* males: M = 7.7 (SD = 1.5), females: M = 7.9 (SD = 1.5) 4. *Illness perceptions: perceived effectiveness of treatment to prevent complications (attitude):* males: M = 7.6 (SD = 1.5), females: M = 8.1 (SD = 1.8)	Males: M = 5.3 (SD = 0.9), Females: M = 5.3 (SD = 1.1).	Correlations between change in insulin adherence and change in the diabetes personal beliefs: 1. *Perceived seriousness of diabetes (risk perceptions):* (not significant)** 2. *Perceived impact of diabetes (risk perceptions):* (not significant)** 3. *Perceived effectiveness of treatment to control diabetes (attitude):* (not significant)** 4. *Perceived effectiveness of treatment to prevent complications (attitude):* (not significant)**	Using two-by-two analyses of variance (with time as a within-subjects factor and gender as a between-subjects factor), girls reported that their diabetes was more serious ($F = 7.13$, $df = 1$, $p = .01$) and had a greater impact on their life ($F = 4.95$, $df = 1$, $p = .05$). Age, duration of diabetes, and socioeconomic status were not associated with injection behavior, or any of the personal models' constructs
Skinner et al., 2002	1. *Illness perceptions: perceived threat of diabetes (risk perceptions):* males: M = 2.79 (SD = 0.82), females: M = 2.57 (SD = 0.79) 2. *Illness perceptions: perceived impact of diabetes (risk perceptions):* males: M = 3.25 (SD = 0.86), females: M = 3.24 (SD = 0.87) 3. *Illness perceptions: perceived effectiveness of treatment to control diabetes (attitude):* males: M = 3.57 (SD = 0.65), females: M = 3.68 (SD = 0.63) 4. *Illness perceptions: perceived effectiveness of treatment to prevent complications (attitude):* males: M = 3.81 (SD = 0.58), females: M = 4.0 (SD = 0.6)	Males: z = 0.14 (SD = 0.58), Females: z = −0.03 (SD = 0.93)	Correlations with adherence: 1. *Perceived threat of diabetes (risk perceptions):* $r = .23$, $p < .005$ (significant) 2. *Perceived impact of diabetes (risk perceptions):* $r = .09$ (not significant)** 3. *Perceived treatment effectiveness to control diabetes (attitude):* $r = .20$, $p < .005$ (significant) 4. *Perceived treatment effectiveness to prevent complications, (attitude):* $r = .07$ (significant)**	After controlling for multiple comparisons, women reported that their treatment was more likely to prevent complications (M = 4.00, SD = 0.6) than men (M = 3.81, SD = 0.6), $t(396) = 2.80$, $p < .005$. Older participants reported that diabetes had a greater impact on their life ($r = −.18$, N = 403, $p < .001$), and they reported that diabetes was a greater threat to their health ($r = −.18$, N = 402, $p < .001$). Neither duration of illness nor socioeconomic status was associated with any personal model beliefs, or insulin injection behavior

Table 2 continues

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Table 2

Table 2 continues

Author, year	Socio-cognitive determinants (SCDs) (the I-change construct) [M (SD), N (%)]*	Adherence/non-adherence [M (SD), z (SD), N (%)]*	Correlational results between SDCs and adherence/ non-adherence [r, p, t]*	Cofounder results [r, p, t, F, df]*
Farsaei et al., 2014	1. Time consuming (attitude): n = 233 (92.8%) 2. Weight gain (attitude): n = 2 (0.8%) 3. Feeling worse after insulin injection (attitude): n = 6 (2.4%) 4. Experience of hypoglycemia (attitude): not reported 5. Medication cost (attitude): n = 6 (2.4%) 6. Interference with usual daily activities (attitude): n = 38 (15.1%) 7. Interference with meal planning (attitude): n = 53 (21.1%) 8. Interference with physical activities (attitude): n = 120 (47.8%) 9. Injection site pain (attitude): n = 176 (70.1%) 10. Injection site reactions (attitude): n = 120 (47.8%) 11. Belief in negative effects of insulin on overall health (attitude): n = 46 (18.3%) 12. Embarrassment (self-efficacy): n = 122 (48.6%) 13. Difficulties in preparing injection (self-efficacy): (not reported) 14. Forgetfulness (self-efficacy): n = 17 (6.8%) 15. Insulin shortage (self-efficacy): n = 4 (1.6%) 16. Sick days (self-efficacy): n = 18 (7.2%) 17. Difficult to inject (self-efficacy): n = 228 (90.8%) 18. Incapability of self-injection (self-efficacy): n = 79 (31.5%) 19. Lack of sufficient injection instructions	8-Item Morisky Medication Adherence Scale (MMAS-8): high adherence: n = 56 (22.3%), medium: n = 159 (63.4%), low: n = 35 (14.3%) Autocompliance method: Adherent: 99.4% (including participants with type 2 diabetes)	Correlations with non-adherence based on the MMAS-8 method: 1. Time consuming (attitude): p < .01 (significant) 2. Weight gain (attitude): p < .01 (significant) 3. Feeling worse after insulin injection (attitude): p < .01 (significant) 4. Experience of hypoglycemia (attitude): p < .01 (significant) 5. Medication cost (attitude): p .01 (significant) 6. Interference with usual daily activities (attitude): p = .08 (not significant) 7. Interference with meal planning (attitude): p = .29 (not significant) 8. Interference with physical activities (attitude): p = .90 (not significant) 9. Injection site pain (attitude): p = 28 (not significant) 10. Injection site reactions (attitude): p = .66 (not significant) 11. Belief in negative effects of insulin on overall health (attitude): p = .26 (not significant) 12. Embarrassment (self-efficacy): p < .01 (significant) 13. Difficulties in preparing injection (self-efficacy): p < .01 (significant) 14. Forgetfulness (self-efficacy): low adherence: p < .01 (significant) 15. Insulin shortage (self-efficacy): p < .01 (significant) 16. Sick days (self-efficacy): p < .01 (significant) 17. Difficult to inject (self-efficacy): p = .30 (not significant) 18. Incapability of self-injection (self-efficacy): p = .90 (not significant) 19. Lack of sufficient injection instructions (information factors): p = .36 (not significant)	Not reported
Riaz et al., 2014	1. Knowledge regarding diabetes (knowledge): not reported 2. Cost of insulin (attitude): not reported 3. Embarrassment about taking insulin (self-efficacy): N = 118 (60.82%) 4. Frequency of visits to diabetic clinics (information factors): < 2: n = 102 (52.57%), ≥ 2: n = 92 (47.42%) 5. Understanding of prescription (language barrier) (information factors): own language – Urdu, n = 175 (90.20%)	Adherents: n = 23 (11.9%)	Correlations with non-adherence: 1. Knowledge regarding diabetes (knowledge): not reported 2. Cost of insulin (attitude) p-value not reported (reported in the article as significant) 3. Embarrassment of taking insulin (self-efficacy): p = .103 (not significant) 4. Irregularity of follow-up (information factors): p = .20 (not significant) 5. Poor understanding of prescription (information factors): p = .102 (not significant)	

Note. *[M – mean, SD – standard deviation, z – mean standardized score, n – number, % – percentage, r – Pearson correlation coefficient, p – significance level, t – t-test, F – F-statistic, df – degrees of freedom];
**the author was contacted for unreported p-values or correlation coefficient values; no further data were provided.

DISTAL INFORMATION AND OTHER FACTORS

Two studies examined distal information factors, such as poor prescription understanding due to language barrier (Farsaei et al., 2014; Riaz et al., 2014) and irregularity in clinic visits and diabetes education (Riaz et al., 2014); these were not found to be associated with adherence. The study results are represented in Table 2.

RISK OF BIAS IN INCLUDED STUDIES

Findings on the quality of the studies are shown in Appendix 2 in the extended data (AlBurno et al., 2022b). The overall quality of two studies (Skinner et al., 2000; Skinner & Hampson, 2001) was rated high (scored 11 points for using a longitudinal design). Four items (6, 7, 10, and 13) in the NHLBI quality assessment tool were tailored towards longitudinal study designs and therefore were not applicable to the four cross-sectional studies included in this review. Hence, three studies (Farsaei et al., 2014; Griva et al., 2000; Skinner et al., 2002) scored 6-8 and were considered fair quality, while one study (Riaz et al., 2014) was considered poor quality for not reporting on several items such as confounding factors, validation of the questionnaire, etc. Four studies did not report correlation coefficients for the strength and direction of association (Farsaei et al., 2014; Riaz et al., 2014; Skinner et al., 2000; Skinner & Hampson, 2001). Some relevant data were still not provided after contacting all authors of primary studies.

DISCUSSION

This systematic review was performed to critically examine relevant literature and report the SCDs associated with adherence or non-adherence to insulin treatment in late adolescents and young adults with T1D. Few studies over the past two decades have adequately quantified the relationship between insulin adherence and SCDs, despite the negative impact of insulin non-adherence on diabetes outcomes (Cramer, 2004), the recognition that psychosocial factors, such as beliefs, attitudes, and motivation have a greater influence on adherence than personality, metabolic, and demographic factors (Kyngäs, 2000), and that adolescents' personal health behavior is the most important modifiable factor to improve health outcomes (Sawyer et al., 2019). Our use of the ICM model as a framework for the results demonstrated that some of the factors identified in this systematic review were similar to those reported in previous systematic reviews in adults with type 1 and type 2 diabetes (Davies et al., 2013; Jaam et al., 2017), and were mainly related to pre-motivational factors (risk perceptions), motivational factors (attitude, social support, and self-efficacy), and distal information factors.

The correlations between insulin adherence and risk perceptions were mixed. These correlations were assessed cross-sectionally (Griva et al., 2000; Skinner et al., 2002) and longitudinally (Skinner et al., 2000; Skinner & Hampson, 2001) through measuring the consequences of diabetes, which consisted of two elements: the perceived seriousness (threat) and the impact of diabetes on daily life. In one cross-sectional study (Skinner et al., 2002), the perceived seriousness (threat) was linked to insulin adherence but not the perceived impact because it was related to AYAs' emotional reactions to having diabetes. Neither of these elements were found to be associated with insulin adherence in the other cross-sectional study (Griva et al., 2000) or in the longitudinal studies (Skinner et al., 2000; Skinner & Hampson, 2001). Conflicting results were also found elsewhere. A meta-analysis study which examined illness perception beliefs in different conditions and diseases demonstrated that perceptions of the illness having serious consequences were significantly correlated with avoidance coping strategies (e.g., non-adherence) (Hagger & Orbell, 2003). Nevertheless, previous research has also shown that adherent adults with T1 and T2 diabetes had lower perceived consequences of diabetes compared with less adherent patients ($p < .05$) (Davies et al., 2013). Other studies demonstrated that the perceived impact of diabetes, which is related to the short-term effects, was predictive of self-management but not the beliefs about the seriousness of diabetes, which are related to the long-term effects of diabetes (Skinner & Hampson, 1998). The inconsistency of findings in this systematic review is likely due to the questionnaires used, sample size, and the selected population (mainly adolescents and biased toward higher socioeconomic groups) (Skinner et al., 2000). The conflicting results might also be due to variations in AYAs' risk perceptions towards short and long-term complications (Skinner & Hampson, 2001). Wasserman et al. (2017) found that AYAs with T1D may undertake diabetes-specific risk behavior because they outweigh short-term complications (e.g., hyperglycemia resulting from insulin omission or severe hypoglycemia resulting from over-dosing) over the delayed effect of insulin non-adherence on health and well-being (having long-term complications). They may also outweigh immediate emotional and social rewards over the risks of non-adherence. This underscores the need to differentiate between short- and long-term complications when assessing risk perceptions. This implicates the importance of addressing personal beliefs and experiences of the disease and the psychosocial factors related to it for specific populations and settings. Moreover, this systematic review did not find any quantitative studies

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that investigated other motivational factors, such as participants' level of awareness of their own adherence behaviors (cognizance), knowledge about what to do to achieve adherence, or awareness of cues to action. These factors have been shown to be correlated with medication adherence in type 2 diabetes (Vluggen et al., 2020) and in other conditions (De Geest & Sabaté, 2003). Hence, AYAs with T1D should be included in high-quality, well-designed studies to better understand the factors related to awareness and adherence to insulin to optimize adherence and health outcomes.

The findings concerning the importance of attitude beliefs with insulin adherence or non-adherence were inconsistent. The illness perceptions model defines attitude as beliefs about the benefits of treatment to control diabetes and beliefs about preventing complications, and both were found to be positively associated with insulin adherence in one cross-sectional study ($p < .005$) (Skinner et al., 2002), but neither element was found to be a predictor of adherence in two longitudinal studies (Skinner et al., 2000; Skinner & Hampson, 2001). Insulin non-adherence, on the other hand, was associated with a negative attitude (e.g., reported disadvantages of using insulin such as time commitment, weight gain, feeling worse after injections, hypoglycemia experience (Farsaei et al., 2014; Riaz et al., 2014), and medication costs (Farsaei et al., 2014). Other attitude factors, such as interference with usual daily activities, interference with meal planning, interference with physical activities, injection site pain, injection site reactions, and belief in the negative effects of insulin on overall health, were not found to be associated with non-adherence (Farsaei et al., 2014). Previous research has shown that patients' beliefs about their treatment effectiveness are better predictors of regimen adherence than perceived barriers (Harvey & Lawson, 2009), and that the belief that the treatment has no effect on disease control may be indicative of maladaptive behavior (e.g., non-adherence) (Hagger & Orbell, 2003). In this systematic review, other factors have contributed to this inconsistency in findings, such as the questionnaires used, sample size, and the selected population (mainly adolescents and biased toward higher socioeconomic groups) (Skinner et al., 2000). Also, adolescents were on a twice-daily injection regimen, which led to little variability in insulin injections and because adolescents were not acting solely in response to their own beliefs due to strong family involvement (Skinner & Hampson, 2001). Additionally, it is important to distinguish between short- and long-term treatment effectiveness beliefs. The perception of diabetes treatment effectiveness to control diabetes, which is related to short-term effects, is more in line with young people's expectations of positive outcomes, such as improved quality of life. The beliefs on the prevention of complications, on the other hand,

are related to the long-term benefits of avoiding having a negative outcome (complications) (Skinner & Hampson, 2001; Skinner et al., 2002). Previous research also distinguished between rational (cognitive consideration of how advantageous performing a behavior would be) and emotional (emotions created by the prospect of performing a behavior) attitudes (Knops-Dullens et al., 2007). The latter were found to have a greater influence on the intention to perform the behavior (Knops-Dullens et al., 2007). Therefore, it is important to investigate attitude factors in well-designed studies which address short- and long-term effectiveness beliefs, as well as rational and emotional attitudes, confounding factors including patients' characteristics, type of insulin device and number of injections.

Social support was found to have no association with insulin adherence (Skinner et al., 2000). In contrast, support from family and friends was reported to enhance adherence behavior (Miller & DiMatteo, 2013), and that during late adolescence and emerging adulthood, friends' involvement supplements or even replaces parental involvement (Berg et al., 2017). In this review, the lack of association between family and friends' social support and insulin injection relied on a single study (Skinner et al., 2000), which was judged to be of good methodological quality, yet was affected by multiple factors which may undermine the findings. The sample represented mostly adolescents who were mainly using a twice-daily insulin regimen, indicating that they injected at home with the close involvement of their parents, lessening the role for general support measures. On the other hand, the lack of associations between diabetes-specific family and peer support and insulin adherence was related to the questionnaires used (scoring and psychometric properties). This highlights the importance of using validated measures to investigate the impact of social factors on insulin adherence, particularly during the critical transition period from pediatrics to early adulthood.

The findings from the present systematic review regarding self-efficacy were mixed as well. Control beliefs conceptualized as self-efficacy beliefs to control and manage disease were reported to have a significant positive association with insulin adherence ($r = .40$, $p < .001$) (Griva et al., 2000). Insulin non-adherence was significantly correlated with some self-efficacy factors such as embarrassment about insulin injections, difficulties in preparing injections, forgetfulness, insulin shortage, and sick days (Farsaei et al., 2014). However, no correlations were found between insulin adherence and general or diabetes-specific self-efficacy (Griva et al., 2000), nor between insulin non-adherence and difficulties with injection, inability to self-inject (Farsaei et al., 2014), or embarrassment about taking insulin (Riaz et al., 2014). Previous research has showed that adherent adults with

T1 and T2 diabetes had a higher perception of personal control compared with less adherent patients ($p < .05$) (Davies et al., 2013) and that personal control was associated with higher self-efficacy and medication adherence in adults with type 2 diabetes (Kim et al., 2021). Control beliefs can motivate patients to adhere, whereas control disbelief might demotivate them to do so (Griva et al., 2000). A prior systematic review reported high self-efficacy to enhance adherence behavior (Neylon et al., 2013). Reasons for discrepancies in this systematic review's findings may be related to the quality of studies; they were based on studies graded as fair (Farsaei et al., 2014) or poor (Riaz et al., 2014) because they did not address confounding factors and did not use a standardized tool to measure self-efficacy. In Griva et al.'s (2000) study, a non-significant association between adherence and self-efficacy was attributed to the adherence scale applied in the study with a focus on intentional non-adherence to the prescribed regimen rather than non-intentional poor adherence, which evolves around challenging situations such as forgetfulness or miscalls, while the used self-efficacy instruments measured patients' beliefs about their abilities to respond to challenging situations. The authors also argued that having high self-efficacy expectations does not necessarily mean that the person will perform the behavior, and it would be better to study the causal relationship between self-efficacy beliefs and adherence (Griva et al., 2000). A systematic review of adults with T1D found that assessing self-efficacy through general task-oriented skill items such as injecting insulin was rated the highest. Meanwhile, items related to responding to difficult situations, such as adjusting insulin dose based on blood test results, when ill or coping when away from home, received the lowest ratings (Sigurðardóttir, 2005). According to a literature review, adolescents usually find it difficult to adjust insulin doses based on blood glucose results (Berg et al., 2017). Furthermore, the level of self-efficacy associated with the best self-care practices is unknown, as is the best measure of self-efficacy (Sigurðardóttir, 2005). A good conceptual analysis of the multi-faceted efficacy beliefs (modelling, skills mastery experiences, social persuasion, and physical and emotional states) within a specified activity domain (through measuring the level of task and gradations of the full range of situational demands that must be managed) should guide self-efficacy assessments (Bandura, 2006). Therefore, to better understand and predict behavior and hence tailor interventional programs to individual needs, the development and interpretation of self-efficacy assessments should take into consideration more than solely skills mastery but rather different aspects of self-efficacy relevant to the domain.

No associations of insulin non-adherence were found with information factors, such as poor pre-scription understanding (Farsaei et al., 2014; Riaz et al., 2014) or irregularity in clinic visits and diabetes education (Riaz et al., 2014). However, previous research has shown that people with diabetes who did not understand the medical recommendation were reluctant to disclose important information about their insulin use, thus resulting in suboptimal insulin adherence (Robinson et al., 2021). Additionally, irregular diabetes clinic attendance is common in AYAs aged 18-30 years (Young-Hyman et al., 2016), particularly when they transition from pediatric to adulthood diabetes care (Monaghan et al., 2015), and is associated with suboptimal adherence and diabetes complications (Anderson & Wolpert, 2004; Borus & Laffel, 2010). However, the lack of association between information factors and insulin non-adherence could be attributed to omitting measuring and controlling various confounding variables, such as psychological and demographic factors (e.g., education level), which might have impacted the results. These factors were previously demonstrated to affect diabetes-related information seeking behavior (Kuske et al., 2017). It is therefore important that future research focus on adequate information factors and proper transition for AYAs with T1D.

An important finding from this systematic review is establishing the validity and reliability of the measures used in the studies. Considering the few items used to test insulin adherence – ranging from 1 item (Griva et al., 2000), two items (Skinner et al., 2000, 2002; Skinner & Hampson, 2001), to 8 items (Farsaei et al., 2014), or not stated (Riaz et al., 2014) – this highlights the importance of determining the validity and reliability of the measures used. Reliability and validity in research are crucial for reproducible data and accurate findings (Kimberlin & Winterstein, 2008). The same is applicable for motivational measures such as attitude. It is imperative, therefore, that constructs are measured appropriately with a sufficient number of items to ensure that the results are sound. This review also highlights the applicability of using adherence measures to overall self-care behaviors to measure adherence to insulin regimens. A previous review stressed that accurate measurement of specific DSM behaviors can be difficult with the available DSM measures due to the diversity and modest intercorrelation of these behaviors (Gonzalez et al., 2016). Another systematic review which examined adherence to medication in T1 and T2 diabetes concluded that there was a lack of gold standard measures for adherence to medication in diabetes as well as a standard meaning of adherence (Coyle et al., 2013). Additionally, most adherence measures focus mainly on the frequency of adherence behaviors and do not consider the specific individual (e.g., the executive function/cognitive control and responsiveness to social and emotional reward), contextual (e.g., adult supervision and peer-related social

factors), or situational factors that affect adherence (Wasserman et al., 2017), or the dynamic nature of adherence to better fit with the experiences of DSM (Gonzalez et al., 2016). It is also possible that the various insulin devices (injections, injectable pens, and insulin pumps) may affect adherence behavior differently (Weinger & Beverly, 2010), but this was not revealed from the current systematic review. Therefore, the current systematic review encourages using insulin-specific adherence measures that account for the different insulin administration systems to address their impact on adherence and the specific individual, contextual, and situational factors that affect adherence to insulin. Moreover, the SCD measures assessed factors relevant to general or diabetes-related outcomes. Consequently, they may not fully capture the application of SCDs to insulin treatment, emphasizing the need to develop specific assessment tools for SCDs.

Although all studies used probability levels (*p*-values) to report significant associations, a few did not report *p*-values for non-significant associations and/or correlation coefficients for the direction and strength of associations. It is argued that authors sometimes do not present statistically non-significant correlations because of "lack of space and sometimes because these results are not considered interesting or publishable" (Gherman et al., 2011). Furthermore, unmeasured confounding variables, such as diabetes duration, type of insulin administration system, number of daily injections, and presence or absence of complications, or failure to report on whether or not the effect of confounding variables was adjusted during the statistical analysis, may compromise the internal validity of observational studies and increase the risk of bias, and should be controlled for in future studies (Dekkers et al., 2019). Missing data appear to be common in systematic reviews and can potentially influence the outcome of results (Reynders et al., 2017). Similar to previous research (Reynders et al., 2017), some relevant data were still not provided after contacting the authors of primary studies, as can be seen in Table 2.

STRENGTHS AND LIMITATIONS OF THE INCLUDED STUDIES

The quality of the majority of studies was fair to good. Additionally, all studies used a relatively large sample size and drop-out rates were considered low. Furthermore, the majority of studies used valid and reliable measures, which would decrease the risk of bias and increase the generalizability of the results, but the items which measured insulin adherence were limited.

A few limitations should be mentioned. Five studies (Griva et al., 2000; Riaz et al., 2014; Skinner et al.,

2000, 2002; Skinner & Hampson, 2001) used non-specific insulin adherence measures, which measured insulin adherence on limited items, resulting in a lack of variability in reporting this behavior and faced the limitations of self-reported results (Wibowo et al., 2021). This demonstrates the need to use diverse measures that are specific to insulin adherence in future research to overcome the limitations of self-reported measures and better predict adherence and association with determinants. Second, AYAs of the age group 17–24 were not fully represented in all included studies. For example, two studies (Skinner et al., 2000; Skinner & Hampson, 2001) focused on younger adolescents (12-18 years), and only one study (Griva et al., 2000) differentiated between adolescents and young adults in their analysis. Measuring adherence behavior in early emerging adults is especially important because young people manage their diabetes more independently (Baker et al., 2019). Third, four studies (Farsaei et al., 2014; Griva et al., 2000; Riaz et al., 2014; Skinner et al., 2002) used a cross-sectional design, in which causal correlations could not be confirmed. Fourth, some coefficients for relations, whether significant or not, were not reported and not obtainable from the contacted authors, which might have introduced bias in the results (Gherman et al., 2011).

STRENGTHS AND LIMITATIONS OF THIS REVIEW

The current review, conducted using comprehensive search/screening procedures, provided a high level of systematic evidence on the subject of interest. First, in order to enhance the performance and reporting of this systematic review, it followed PRISMA 2020 guidelines (Page et al., 2021), and the published protocol of this review provided evidence of the reliable conduct of the study (AlBurno et al., 2022a). Second, four databases were searched, which included a specialized database in the field of behavioral sciences to avoid missing relevant references (Bramer et al., 2017) and to minimize selection bias (Lefebvre et al., 2022). Third, a quality assessment tool was used to assess the risk of bias of the included studies, which has proven adequate inter-rater agreement. Fourth, the search was conducted within a timeframe and was repeated to keep up to date with the most recent research evidence. Fifth, the exclusion of data from older or younger populations helped maintain the focus and validity of the results for AYAs. This targeted approach ensured that conclusions drawn were specific to the relevant age group, improving the precision and relevance of the findings.

The current systematic review has a few limitations as well. First, the number of included studies was limited, which complicated comparisons be-

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tween studies. However, with the systematically formulated search strings using PRESS guidelines, it seems that the overall sample size of the target population was sufficient to draw conclusions. Second, the results may have been further impacted by the limited number of countries in which the studies were conducted. Cultural differences, for example, can greatly influence adherence to insulin therapy. Factors such as the cultural context of healthcare delivery, family involvement, societal expectations around young adults' independence, healthcare access disparities, financial constraints, and societal attitudes toward illness and treatment all play a role in how effectively AYAs manage their T1D. These differences underscore the importance of conducting studies in a broader range of countries to better understand challenges with insulin adherence among AYAs. Third, despite the fact that most of the included studies provided definitions of insulin adherence and used valid and reliable measures, the variety in the adherence measures used among the included studies and in adherence definitions hampered the comparison of adherence rates across studies. It is acknowledged that measuring adherence to therapy in T1D is difficult due to variations in adherence definitions (Datye et al., 2015). Fourth, despite the fact that a rigorous literature search was conducted, it is still possible that potentially relevant studies could have been excluded during title and abstract screening. For example, because there are no internationally accepted definitions of adolescence and young adults and the meaning of the terms varies and might overlap in different countries and in the literature (United Nations, n/d), articles that included pediatrics, children, or adult populations in the titles or abstracts were excluded, although they might have included our targeted population. Even after reading the full article, the lack of reporting age and/or age range made the decision to include challenging in some cases. Additionally, excluding broader age data might have narrowed the total range of generalizability. Fifth, there is a shortage of recent studies, which highlights the need for future original quantitative studies to investigate the determinants of insulin adherence among AYAs with T1D. Other relevant evidence may have been missed due to excluding gray literature and articles published in non-English languages (Lefebvre et al., 2022). Despite these limitations, the present review provides a high level of systematic evidence on the subject of interest.

CONCLUSIONS AND RECOMMENDATIONS

Awareness of the key socio-cognitive determinants of behaviors will help healthcare professionals dealing with AYAs with T1D to focus their resources to develop strategies to assist patients in the numerous daily decisions they need to take to manage their insulin administration by targeting these SCDs. The findings will also be helpful for developing health policy planning that will encourage the incorporation of SCDs of behavior into adherence-improving strategies as well as to integrate these strategies into diabetes care to enhance the quality and outcomes of diabetes care. This study has raised numerous areas for further research. The findings from this additional research will help lay the foundation for more effective interventions, which in turn would reduce the enormous burden of adherence to insulin in AYAs with T1D. Few studies were found that paid attention to the importance of motivational factors to understanding adherence in AYAs with T1D. Our findings indicate the importance of addressing insulin adherence and its related motivational factors (attitude, social influence, and self-efficacy) for specific populations and settings. It also underscores that adherence measures need to be age-specific and validated for insulin behavior. Yet, more attention to these factors and better measurement are needed to better understand (non-) adherence in this group. Many studies used quite brief questionnaires that did not assess all relevant constructs and that often used few items. For instance, for attitude, it is important to distinguish not only short- and long-term outcome expectations but also rational and emotional outcome expectations, as research has shown the importance of the latter (Knops-Dullens et al., 2007). There is a shortage of studies describing other important factors, such as a patient's level of cognizance about his or her adherence behavior; knowledge of the importance of adherence and how to realize it; and plans to prepare for sufficient adherence and how to achieve this under a variety of situations (action planning). Studies show that these factors may have utility to promote adherence to other medications in type 2 diabetes (Vluggen et al., 2020) and in other conditions (De Geest & Sabaté, 2003), and goal setting to improve blood glucose self-monitoring (Patton, 2015). Additionally, a scoping review has shown that goal setting and action planning are linked to adherence to lifestyle behaviors and to medication for other conditions (Lenzen et al., 2017). Furthermore, factors related to adherence to various insulin delivery systems such as insulin pumps have not been adequately addressed in the literature (Pauley et al., 2021) and need further investigation, because such factors may vary according to insulin device type. Therefore, to better understand how awareness factors, motivational factors, and action planning factors relate to insulin adherence and how to improve adherence and health outcomes, more research is required in quality-designed studies that use detailed and comprehensive measures for assessing adherence to insulin delivered by various insulin systems.

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UPDATING THIS REVIEW

An updated systematic search for new studies (Cumpston & Chandler, 2022) was conducted from July 18 to July 24, 2023, in the original databases using the original search methodology, with a focus on publications from the years 2021 to 2023. A total of 99 articles were retrieved (PubMed = 31, Embase = 10, WoS = 23, PsycINFO = 35). After the removal of one duplicate and six articles (4 theses and 2 articles not written in English), 92 articles were included for screening based on titles. An additional article was added from cross-reference checks. Out of the 93 screened titles, six were included in the abstract/title screening, but none met the inclusion criteria. The reasons for exclusion included: the inclusion of either T1D or T2D without distinguishing between them in the analysis, not on adherence or SCDs, etc. (see Appendix 5 in the extended data for further information; AlBurno et al., 2022b).

To identify relevant systematic reviews and/or meta-analyses on insulin adherence or compliance published between 2020 and 2023, a literature search was performed using PubMed, Embase, Web of Science, and PsycINFO. We retrieved a total of 442 studies from our searches (after duplicate removal), and an additional nine studies were added through other sources (see Appendix 6: extended data; AlBurno et al., 2022b). After screening this total of 451 titles, seven studies were included for abstract screening. Three studies were excluded based on abstracts because either they concerned people with T2D or used ecological momentary assessment. Four studies (3 systematic reviews and 1 meta-analysis) were selected for a full article review (Alexandre et al., 2021; Azharuddin et al., 2021; Gonzalez, 2023; Robinson et al., 2021). The PEO (population, exposures, and outcome) elements and/or study design of these studies differed from our systematic review in more ways than one. Some of the notable differences are as follows. Firstly, the reviewed studies included a broader age range, encompassing both children and/or the elderly and/or people with either T1D or T2D. Secondly, they also considered various exposure factors, such as patient factors (e.g., demographic, psychological, and behavioral factors) and/or non-patient factors (e.g., therapy-related factors, healthcare system factors, socio-economic factors, social factors). Thirdly, they examined adherence to various DSM behaviors, any individual behaviors, or adherence/non-adherence to treatment. Fourthly, they covered a diverse set of study types, including quantitative, qualitative, and interventional studies.

Additionally, to ensure a comprehensive search, we conducted a thorough screening of the full reference lists and citations of these four studies, using PubMed as the indexing source. After removing any duplicates in EndNote, none of the screened citations and references met the eligibility criteria for inclusion in the updated search. For further details, see Appendix 6 (AlBurno et al., 2022b).

In conclusion, despite conducting repeated searches, no additional articles were found, highlighting the scarcity of research on insulin adherence and its determinants in AYAs with T1D. This paucity of available studies underscores the pressing need for further research in this area to better understand the factors influencing insulin adherence among AYAs with T1D. By expanding the evidence base, we can develop more effective strategies to support these individuals in managing their condition and ultimately improve their health outcomes.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are openly available in Figshare at https://doi.org/10.6084/m9.figshare.20502567.v10.

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