



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

Hanan AlBurno¹ · Liesbeth Mercken^{1,2} · Hein de Vries¹ · Dabia Al Mohannadi⁴ · Stefan Jongen³ · Francine Schneider¹

Received: 5 October 2021 / Accepted: 9 May 2022 / Published online: 26 May 2022
© The Author(s) 2022

Abstract

Objective This systematic review aims to investigate the key socio-cognitive determinants associated with adherence/non-adherence to insulin treatment in late adolescents and young adults in the age range of 17–24 years with T1D.

Methods A pre-specified search strategy will be used to search for studies in the electronic databases and citation indexes: PubMed, EMBASE, Web of Science, and PsycINFO. Two researchers will screen the title and the abstract independently, then will read and critically appraise the full text of each included study. A third independent reviewer will resolve disagreements in data extraction until consensus. Data will be extracted using the Population, Exposure, Outcomes, Study characteristics framework. Study selection will follow the updated guideline for reporting systematic reviews (PRISMA 2020) and will take place from 15 October 2021 to 1 January 2022. The methodological quality and risk of bias of the observational studies will be assessed by the JBI Critical Appraisal Checklist for Cohort and JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies.

Results A qualitative narrative synthesis will present the characteristics and the quality of studies and the outcomes of concern.

Conclusion Based on the contemporary literature, this review will synthesize the evidence on the socio-cognitive determinants associated with adherence/non-adherence to insulin treatment in late adolescents and young adults in the age range of 17–24 years with T1D. The findings will help design patient-centered interventions to promote adherence to insulin in this age group, guide patients' consultations and diabetes self-management education (DSME) programs.

Protocol registration: PROSPERO ID: CRD42021233074.

Keywords Socio-cognitive · Insulin · Adherence · Non-adherence · Type 1 diabetes · Adolescents · Young adults · Systematic review

✉ Hanan AlBurno
H.Burno@maastrichtuniversity.nl

✉ Francine Schneider
francine.schneider@maastrichtuniversity.nl

Liesbeth Mercken
Liesbeth.mercken@ou.nl

Hein de Vries
hein.devries@maastrichtuniversity.nl

Dabia Al Mohannadi
dalmohannadi@hamad.qa

Stefan Jongen
stefan.jongen@maastrichtuniversity.nl

¹ Care and Public Health Research Institute (CAPHRI),
Maastricht University, Maastricht, The Netherlands

² Department of Health Psychology, Faculty of Psychology,
Open University of The Netherlands, Heerlen,
The Netherlands

³ Faculty of Science and Engineering, Maastricht University,
Maastricht, The Netherlands

⁴ Department of Endocrinology and Diabetes, Hamad General
Hospital, Doha, Qatar

Introduction

Type 1 diabetes (T1D) is a global health problem with increasing prevalence at 3–5% yearly [1–3]. Although T1D sometimes appears during adulthood, it usually occurs during childhood or adolescence and is treated with insulin therapy. Despite the advancements in insulin administration systems, insulin adherence continues to pose a significant challenge for adolescents and young adults (AYAs) with T1D [4–7]. Adherence to insulin can be defined as administering the correct dose at the right time and/or frequency in accordance with a mutually agreed-upon treatment regimen [8, 9].

Evidence suggests that the rate of insulin non-adherence in AYAs is high [4, 10–12], ranging from 23–77%, with a higher rate in developing countries [13]. Research has demonstrated that non-adherence to insulin is associated with increased glycated hemoglobin (HbA1c) level [5, 14], diabetic ketoacidosis [15], increased hospitalization [16], and long-term complications [15–17]. The latter includes microvascular and macrovascular complications leading to increased morbidity and mortality in people with T1D [4, 8, 17]. On the other side, the association between greater adherence and improved clinical outcomes in AYAs with T1D is evident [5, 6, 14]. Insulin non-adherence can occur intentionally or unintentionally and involves situations where adolescents and young adults did not fill their insulin prescriptions [17, 18], reduced or omitted doses [4, 7, 19]. The latter may occur for various reasons, such as fear of hypoglycemia [20], weight control [4, 7, 19], interference with daily routine, forgetfulness [13], problems with coping with peers [21], and social stigma [22, 23]. Sometimes AYAs unintentionally administered the wrong dose [21, 24]. Due to the negative (health) consequences of sub-optimal adherence, it is imperative to understand adherence/non-adherence behaviors and their factors.

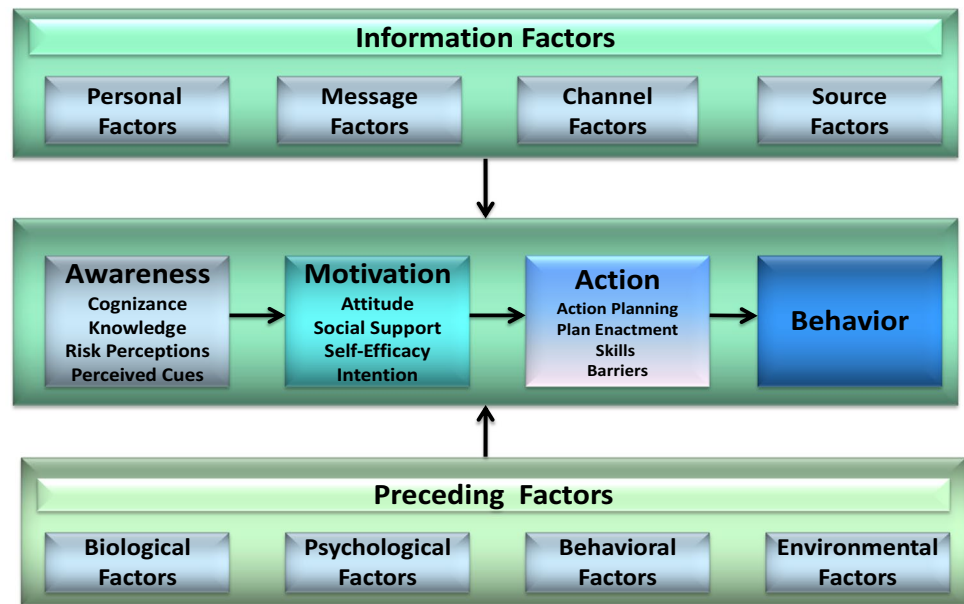
Medication adherence is affected by multiple interacting factors [4, 25, 26]. Some of these factors are relatively fixed factors, such as socio-demographic (SD) factors (e.g., age, gender, ethnicity, personality, etc.) [14, 27–29] and socioeconomic (SE) factors (e.g., cost of treatment) [5, 27–29]. For example, findings revealed that AYAs were the least adherent and had poorer diabetes control compared with children and older patients [4–7, 18]. A systematic review among adolescents with T1D found that female sex was associated with non-adherence in more than one study [30]. Multiple studies involving T1D demonstrated eating disorders were more common in females than in males [31, 32]. The prevalence of eating disorders increased with age, affecting up to 40% of young adult females with T1D [33]. Eating disorders were found to be associated with lower insulin adherence and higher HbA1c

[11, 19, 34]. Other factors are either difficult to modify, such as certain affect psychosocial factors (e.g., diabetes emotional distress, depression, anxiety, etc.) [14, 19, 30, 35] or partly unmodifiable such as medication regimen factors including the complexity of insulin regimen [5, 13, 36], type of administration devices [4, 14, 27], and insulin side effects (e.g., hypoglycemia).

Certain factors, such as socio-cognitive factors, are, however, more likely to be modifiable [4, 26, 27]. Having insight into these modifiable factors can help to inform future interventions aimed at improving adherence through minimizing barriers and maintaining/promoting facilitators. There is a growing body of knowledge on the various psychological/behavioral models used to examine the socio-cognitive factors that influence adherence to insulin [37]; still, all potentially relevant psychosocial factors were not yet considered in an integrated way [38]. Holmes and colleagues (2014) argue that within the theoretical models, researchers often focus explicitly on evaluating variables that are considered proximal (close) rather than distal to adherence behavior [39]. Hence, the I-Change model (ICM) [40] will be the leading theoretical frame for the present review (Fig. 1). The ICM integrates broader determinants of personal and environmental factors for the diagnosis of behavior, ranging from the individual 's degree of health literacy and knowledge to the social environment and setting for carrying out and maintaining the 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), and distal information factors. This is particularly relevant for diabetes control as multiple empirical studies have shown that sets of interactively integrated factors account for variations in adherence to the prescribed recommendations [25, 41, 42].

Several studies have investigated and identified important socio-cognitive factors within adolescents and/or young adults. Some were related to pre-motivational factors such as knowledge and expectancies [43, 44], perceived severity of the disease, perceived susceptibility or vulnerability to the disease process, perceived barriers/costs to the action, and cues to action [45, 46]. Regarding motivational factors, results by de Weerd and colleagues (1990) showed that attitude was an essential determinant of active self-care of AYAs along with features of their social environment [47]. Other studies showed positive correlations of perceived self-efficacy and outcome expectancies with insulin adherence [48, 49]. Others identified the role of the social influence of family, peers, and the healthcare system on adherence [50–52]. Within the post-motivational factors, past studies demonstrated that the coping mechanism and appraisal of coping/ progress would modify the representation and/or coping behaviors [53, 54]. Regarding distal information

Fig. 1 The I-Change Model. This figure has been reproduced with permission from de Vries H. An integrated approach for understanding health behavior; the I-change model as an example. *Psychol Behav Sci Int J.* 2017;2(2):555–85. <https://doi.org/10.19080/PBSIJ.2017.02.555585>



factors, studies highlighted considering features such as level, frequency, type, relevance to the recipient, and quality of information to provide personalized information to AYAs [55, 56], and how the lack of information has impacted diabetes management negatively [57].

Systematic reviews that looked at socio-cognitive determinants of insulin adherence among people with T1D mainly focused on adults (i.e., Sigurdardóttir et al., 2005; Gherman et al., 2011; Davies et al., 2013) [27, 58, 59]. 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 behaviors including diet, physical activity, self-monitoring of blood glucose and medication adherence (i.e., Coyle et al., 2013; Neylon et al. 2015; Martinez et al., 2016) [28, 30, 60] and/or did not exclusively relate to T1D (included patients with either type 1 or type 2 diabetes), (i.e., Nagasawa et al. 1990; Coyle et al., 2013; Gonzalez et al., 2016; Robinson et al., 2021) [29, 60–62] and/or focused mainly on a few determinants (i.e., Young et al., 2013; Datye et al., 2015; Neylon et al. 2015) [5, 28, 63]. Hence, the relevance of these findings for AYAs with T1D is unclear. One narrative review [5] 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.

To date, a wide range of other socio-cognitive determinants such as those that predispose one to action (awareness factors and cues to action) and those that shift a person from being predisposed to action into an action state (clear action and coping planning and self-regulation skills) are not often investigated in the T1D systematic

reviews. Overall, there is a gap in the systematic evidence that addresses the integrative socio-cognitive determinants of insulin adherence among late adolescents and young adults with T1D. Therefore, a comprehensive systematic evaluation of the evidence on the socio-cognitive determinants that predict adherence/non-adherence to insulin treatment among this age group is warranted. 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 patients with T1D. Therefore, this review aims to identify the key socio-cognitive determinants influencing adherence/non-adherence to insulin administration in late adolescents and young adults in the age range of 17–24 years with T1D. In order to ensure the systematic search of available literature, the Population, Exposure, Outcomes (PEO) strategy [64, 65] guided the formulation of the research question for this review.

Methods

The methods of this systematic review have been developed and reported in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA-P) [66] (see Annexure 1—PRISMA-P completed checklist) [67]. The study protocol is registered with the International Prospective Register of Systematic Reviews (PROSPERO) with ID: CRD42021233074.

Inclusion and exclusion criteria

Types of eligible studies

Studies will be selected for review if they were peer-reviewed cohort studies employing cross-sectional, longitudinal prospective, and retrospective cohort or mixed methods designs, published from 2000 to 2020 and written in English. Randomized and non-randomized comparative studies of interventions and studies investigating factors other than socio-cognitive determinants, such as only socio-demographic and/or only psychological factors will be excluded from the review. The reason for this is that these studies do not address the research question of interest. Besides, previous reviews [5, 28, 68–70] have provided evidence for them. Commentaries, letters, and editorials will also be excluded.

Population

Studies will be selected for review if they included adolescents and/or young adults in the age range of 17–24 years with clinical diagnosis of T1D. There will be no restrictions on the gender or ethnicity of participants. Since adherence is dynamic in nature [71], there will be no restrictions on 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 will be excluded because each of these population groups has conditions that affect the nature of insulin adherence behavior.

Exposure variable(s)

Studies which investigated one or more of the socio-cognitive determinants associated with insulin adherence/non-adherence will be included. ICM guided the selection of the primary exposures of interest. Therefore, studies reporting on patient motivation, awareness of behavior and illness perception, awareness of risk perception, knowledge, cues of action, attitudes, self-efficacy, social influence, social norms, social modeling, action planning, coping planning, information, self-regulation skills, and service-related factors will be included in the review.

Outcome variable(s)

Studies which used the participants' adherence/non-adherence to insulin administration as the main outcome will be included. The secondary outcome will be the quantified association between any measured socio-cognitive

determinant and adherence (if any). For more information about the outcome, please see *Appendix 3 in the extended data* [67].

Search strategy

A pre-specified search strategy will be used to search for studies in the electronic databases and citation indexes: PubMed, EMBASE, Web of Science, and PsycINFO databases. We aimed to achieve an optimal combination of databases to avoid missing relevant references [72]. The literature search will be limited to the English language and to articles published between 2000 to 2020 and will take place on 15 October 2021 until 1 January 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 [73]. A decision to identify studies only in the English language was undertaken due to time and budget resource limits [74, 75]. The decision on publication years was undertaken, considering 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 [70], therefore, we attempted to balance the thoroughness of searching published articles within a timeframe which is not too narrow (to minimize bias of missing articles) [75], nor too wide (to keep up-to-date with the most recent research evidence relating to systematic reviews in the social sciences [76] and the advancements in behavioral science in T1D) [77]. Reference lists from published studies and relevant reviews will be reviewed for additional papers not indexed in the databases searched, and when necessary, corresponding authors will be contacted for additional information [78].

A search strategy combining MeSH and Emtree terms in PubMed and EMBASE, respectively, and free-text words (including term explosion) in the titles and abstracts will be used [79, 80]. The list of systematically formulated search strings containing four index terms: (1) population, (2) exposure, (3) outcomes, and (4) study design is peer reviewed by SJ using the Press peer review of electronic search strategies guidelines and any necessary adjustments will be made before running the search [81]. The PubMed search strategy is available as *Extended data* (Appendix 1) [67].

Study selection

Study selection will follow the updated guideline for reporting systematic reviews (PRISMA 2020) [82] and will take place from 15 October 2021 to 1 January 2022. Duplicate records identified from database search will be first removed electronically in Endnote X9 following the method described by Bramer and colleagues (2016) [83]. Secondly, two

researchers (HB and FS), working independently to minimize bias, will screen titles of all citations derived from the search. Thirdly, they will screen abstracts for eligibility. Finally, they will read and critically appraise the full text of each included study. During this process, the two researchers will discuss their findings; in case of uncertainty to either include or exclude the study, the full article will be read [84]. Furthermore, if any discrepancies in study selection between the two researchers still exist, a third researcher (LM) will be included in the discussion until consensus is reached.

Assessment of methodological quality and risk of bias

Two separate reviewers will assess the quality of the included studies using The Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Cohort Studies and JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies [78]. The overall quality and risk of bias will be determined based on JBI guidelines [85]. A third reviewer will judge the disagreement, if any. These tools 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 [86]. JBI Critical Appraisal Checklists are depicted in Appendix 2 (*Extended data*) [67]. The number of positive answers to the questions will lead to the final score of the study. Studies will be classified as “high risk of bias (low quality)”, “moderate risk of bias (moderate quality)” and “low risk of bias (high quality)” if they score 0–3, 4–5, and 6–8 respectively, using the checklist for analytical cross-sectional studies, and 0–3, 4–7, and 8–11 respectively, using the checklist for cohort studies.

Data extraction

We will use the population, exposure, outcomes, and study characteristics framework to extract data. Two reviewers will extract data independently (HB and LM), a third independent reviewer (FS) will resolve disagreements in data extraction until consensus. Data will be extracted using a standardized and piloted extraction form adapted from Cochrane Public Health Group Data Extraction and Assessment Template [87]. The following three types of data will be extracted from selected studies: a) study data, b) outcome data, and c) study quality. Study data will include: 1) publication; 2) population; 3) study characteristics; 4) exposure; and 5) results and findings. Outcome data will relate to primary and secondary outcomes (see *Appendix 3 in the extended data*) [67]. Adherence is determined by using one or a combination of adherence to insulin measures (the commonly reported methods including the (adjusted) medication possession ratio, proportion of days covered (PDC), persistence,

daily average consumption (DAC), and the Morisky Medication Adherence Scale (MMA) or by indirect methods such as using prescription claims, pharmacy/medical records or self-report questionnaires, visual analogue scale or by using cell-phone real-time assessment and computerized logbooks [17, 88, 89].

Data synthesis

Meta-analysis will not be performed due to the expected heterogeneity across studies, because of the variety of socio-cognitive determinants used in eligibility criteria and/or methods used to measure insulin adherence. Hence, a qualitative narrative synthesis will be performed and summarized in a table of findings using GRADEpro, which will present the characteristics and quality of studies, and the outcomes of concern [90].

Discussion

This systematic review will be performed to critically examine relevant literature and report the socio-cognitive determinants associated with adherence/non-adherence to insulin treatment in late adolescents and young adults with T1D. The findings will help design patient-centered interventions to promote adherence to insulin in this age group, and guide patients' consultations and diabetes self-management education (DSME) programs.

Several systematic reviews have identified patient-perceived barriers as predictive of non-adherence to self-care recommendations in patients with type 1 or type 2 diabetes [27, 62, 91]. However, unlike our proposed review, findings from previously published systematic reviews were not specific to late adolescents and young adults, nor to type 1 diabetes, and/or to insulin adherence. Given, the hazardous consequences of non-adherence to insulin on diabetes outcomes [18], in addition to the availability of evidence which shows that psychosocial factors such as beliefs, attitudes, and motivation have a greater influence on adherence than personality, metabolic, and demographic factors [92]. Moreover, patients' adherence to different domains of DSM is not uniform [6]. Therefore, our systematic review, grounded in theory, will fill this gap in the literature.

The proposed review is expected to have the following strengths. First, in order to enhance the performance and reporting of this systematic review, it will follow PRISMA 2020 guidelines [82], and will be conducted according to this reproducible protocol, which will provide evidence of the reliable conduct of the study [62, 91]. Second, four databases will be searched, which include a specialized database in the fields of behavioral sciences to avoid missing relevant references [72] and to minimize selection bias [75]. Third,

the validated JBI checklist tools will be used to assess risk of bias of the included studies which address both the validity and reliability of a study [93]. However, the review is expected to have a few limitations. The various direct and indirect adherence measures to insulin treatment may hamper the comparison of adherence rates across studies. Other relevant evidence may be missed due to excluding Gray literature and articles published in a non-English language [75]. Despite these limitations, the proposed review will provide high level of systematic evidence on the subject of interest.

Data availability

Underlying data
No data is associated with this article.

Declarations

Conflicts of interest The authors have no conflicts of interest to declare that are relevant to the content of this article.

Open Access This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by/4.0/>.

References

1. The World Health Organization. Global report on diabetes. https://apps.who.int/iris/bitstream/handle/10665/204871/9789241565257_eng.pdf;jsessionid=FCCE83FEB7AAC98EF0C0E19FD43F58D0?sequence=1. Accessed 2 Jan 2021.
2. Shahbazi H, Ghofranipour F, Amiri P, Rajab A. Factors affecting self-care performance in adolescents with type 1 diabetes according to the pen-3 cultural model. *Int J Endocrinol Metab.* 2018;16(4): e62582. <https://doi.org/10.5812/ijem.62582>.
3. Razavi Z, Karimpourian A, Aramian LM, Bazmamoun H. Demographic characteristics of type 1 diabetic children and adolescents in Hamadan. *Iran J Res Health Sci.* 2015;15(3):196–9.
4. Borus JS, Laffel L. Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Curr Opin Pediatr.* 2010;22(4):405–11. <https://doi.org/10.1097/MOP.0b013e32833a46a7>.
5. Datye KA, Moore DJ, Russell WE, Jaser SS. A review of adolescent adherence in type 1 diabetes and the untapped potential of diabetes providers to improve outcomes. *Curr Diab Rep.* 2015;15(8):1–9. <https://doi.org/10.1007/s11892-015-0621-6>.
6. Gandhi K, Vu BK, Eshtehardi SS, et al. Adherence in adolescents with Type 1 diabetes: strategies and considerations for assessment in research and practice. *Diabetes Manag (Lond).* 2015;5(6):485–98. <https://doi.org/10.2217/dmt.15.41>.
7. McCarthy MM, Grey M. Type 1 diabetes self-management from emerging adulthood through older adulthood. *Diabetes Care.* 2018;41(8):1608–14. <https://doi.org/10.2337/dc17-2597>.
8. The World Health Organization (WHO). Adherence to long term therapy: evidence for action. 2003. https://www.who.int/chp/knowledge/publications/adherence_full_report.pdf. Accessed 2 Jan 2021
9. Gast A, Mathes T. Medication adherence influencing factors-an (updated) overview of systematic reviews. *Syst Rev.* 2019;8(1):112–22. <https://doi.org/10.1186/s13643-019-1014-8>.
10. Diabetes Control and Complications Trial Research Group. Effect of intensive diabetes treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus: diabetes control and complications trial. *J Pediatr.* 1994;125(2):177–88. [https://doi.org/10.1016/S0022-3476\(94\)70190-3](https://doi.org/10.1016/S0022-3476(94)70190-3).
11. Peyrot M, Rubin RR, Kruger DF, Travis LB. Correlates of insulin injection omission. *Diabetes Care.* 2010;33(2):240–5. <https://doi.org/10.2337/dc09-1348>.
12. Tewabe T, Kindie S. Level of insulin adherence among diabetes mellitus patients in Felege Hiwot Referral Hospital, Bahir Dar, Northwest Ethiopia, 2017: a cross-sectional study. *BMC Res Notes.* 2018;11(1):295–305. <https://doi.org/10.1186/s13104-018-3398-2>.
13. Almeda-Valdes P, Palacio Ríofrio J, Zamudio Coronado KW, et al. Factors associated with insulin nonadherence in type 1 diabetes mellitus patients in Mexico. *Int J Diabetes Metab.* 2020;25(3–4):139–47. <https://doi.org/10.1159/000502903>.
14. Gloaguen E, Bendelac N, Nicolino M, et al. A systematic review of non-genetic predictors and genetic factors of glycosylated haemoglobin in type 1 diabetes one year after diagnosis. *Diabetes Metab Res Rev.* 2018;34(8): e3051. <https://doi.org/10.1002/dmrr.3051>.
15. Kanikarla-Marie P, Jain SK. Hyperketonemia and ketosis increase the risk of complications in type 1 diabetes. *Free Radic Biol Med.* 2016;95:268–77. <https://doi.org/10.1016/j.freeradbiomed.2016.03.020>.
16. Cengiz E, Xing D, Wong JC, et al. Severe hypoglycemia and diabetic ketoacidosis among youth with type 1 diabetes in the T1D exchange clinic registry. *Pediatr Diabetes.* 2013;14(6):447–54. <https://doi.org/10.1111/pedi.12030>.
17. Doggrell SA, Chan V. Adherence to insulin treatment in diabetes: can it be improved? *J Diabetes.* 2015;7(3):315–21. <https://doi.org/10.1111/1753-0407.12212>.
18. Cramer JA. A systematic review of adherence with medications for diabetes. *Diabetes Care.* 2004;27(5):1218–24. <https://doi.org/10.2337/diacare.27.5.1218>.
19. Berger G, Waldhoer T, Barrientos I, et al. Association of insulin-manipulation and psychiatric disorders: a systematic epidemiological evaluation of adolescents with type 1 diabetes in Austria. *Pediatr Diabetes.* 2019;20(1):127–36. <https://doi.org/10.1111/pedi.12784>.
20. Almaghaslah D, Abdelrhman AK, AL Masdaf SK, et al. Factors contributing to non-adherence to insulin therapy among type 1 and type 2 diabetes mellitus patients in Asser region, Saudi Arabia. *Biomed Res.* 2018;29(10):2090–5. <https://doi.org/10.4066/biomedresearch.29-18-503>.
21. Schober E, Wagner G, Berger G, et al. Prevalence of intentional under- and overdosing of insulin in children and adolescents with type 1 diabetes. *Pediatr Diabetes.* 2011;12(7):627–31. <https://doi.org/10.1111/j.1399-5448.2011.00759.x>.
22. Mulvaney SA, Hood KK, Schlundt DG, et al. Development and initial validation of the barriers to diabetes adherence measure for adolescents. *Diabetes Res Clin Pract.* 2011;94(1):77–83. <https://doi.org/10.1016/j.diabres.2011.06.010>.

23. Doosti-Irani M, Abdoli S, Parvizy S, Fatemi NS. Overcoming diabetes-related stigma in Iran: a participatory action research. *Appl Nurs Res*. 2017;36:115–21. <https://doi.org/10.1016/j.apnr.2017.06.008>.
24. Trief PM, Cibula D, Rodriguez E, et al. Incorrect insulin administration: a problem that warrants attention. *Clin Diabetes*. 2016;34(1):25–33. <https://doi.org/10.2337/diaclin.34.1.25>.
25. Martin LR, Williams SL, Haskard KB, Dimatteo MR. The challenge of patient adherence. *Ther Clin Risk Manag*. 2005;1(3):189–99.
26. Cox L, Hunt J. Factors that affect adolescents' adherence to diabetes treatment. *Nurs Child Young People*. 2015;27(1):16–21. <https://doi.org/10.7748/ncyp.27.1.16.e565>.
27. Davies MJ, Gagliardino JJ, Gray LJ, et al. Real-world factors affecting adherence to insulin therapy in patients with type 1 or type 2 diabetes mellitus: a systematic review. *Diabet Med*. 2013;30(5):512–24. <https://doi.org/10.1111/dme.12128>.
28. Neylon OM, O'Connell MA, Skinner TC, Cameron FJ. Demographic and personal factors associated with metabolic control and self-care in youth with type 1 diabetes: a systematic review. *Diabetes Metab Res Rev*. 2013;29(4):257–72. <https://doi.org/10.1002/dmrr.2392>.
29. Gonzalez JS, Tanenbaum ML, Commissariat PV. Psychosocial factors in medication adherence and diabetes self-management: implications for research and practice. *Am Psychol*. 2016;71(7):539–51. <https://doi.org/10.1037/a0040388>.
30. Martinez K, Frazer SF, Dempster M, et al. Psychological factors associated with diabetes self-management among adolescents with type 1 diabetes: a systematic review. *J Health Psychol*. 2018;23(13):1749–65. <https://doi.org/10.1177/1359105316669580>.
31. Colton P, Rodin G, Bergenstal R, Parkin C. Eating disorders and diabetes: introduction and overview. *Diabetes Spectr*. 2009;22(3):138–42. <https://doi.org/10.2337/diaspect.22.3.138>.
32. Scheuing N, Bartus B, Berger G, et al. Clinical characteristics and outcome of 467 patients with a clinically recognized eating disorder identified among 52,215 patients with type 1 diabetes: a multicenter German/Austrian study. *Diabetes Care*. 2014;37(6):1581–9. <https://doi.org/10.2337/dc13-2156>.
33. Pinhas-Hamiel O, Hamiel U, Levy-Shraga Y. Eating disorders in adolescents with type 1 diabetes: Challenges in diagnosis and treatment. *World J Diabetes*. 2015;6(3):517–26. <https://doi.org/10.4239/wjdv6.i3.517>.
34. Nip ASY, Reboussin BA, Dabelea D, et al. Disordered eating behaviors in youth and young adults with type 1 or type 2 diabetes receiving insulin therapy: the search for diabetes in youth study. *Diabetes Care*. 2019;42(5):859–66. <https://doi.org/10.2337/dc18-2420>.
35. van Duinkerken E, Snoek FJ, de Wit M. The cognitive and psychological effects of living with type 1 diabetes: a narrative review. *Diabet Med*. 2020;37(4):555–63. <https://doi.org/10.1111/dme.14216>.
36. Jaam M, Awaisu A, Mohamed Ibrahim MI, Kheir N. A holistic conceptual framework model to describe medication adherence in and guide interventions in diabetes mellitus. *Res Social Adm Pharm*. 2018;14(4):391–7. <https://doi.org/10.1016/j.sapharm.2017.05.003>.
37. Hood KK, Hilliard M, Piatt G, Ievers-Landis CE. Effective strategies for encouraging behavior change in people with diabetes. *Diabetes Manag (Lond)*. 2015;5(6):499–510.
38. Patton DE, Hughes CM, Cadogan CA, Ryan CA. Theory-based interventions to improve medication adherence in older adults prescribed polypharmacy: a systematic review. *Drugs Aging*. 2017;34(2):97–113. <https://doi.org/10.1007/s40266-016-0426-6>.
39. Holmes EA, Hughes DA, Morrison VL. Predicting adherence to medications using health psychology theories: a systematic review of 20 years of empirical research. *Value Health*. 2014;17(8):863–76. <https://doi.org/10.1016/j.jval.2014.08.2671>.
40. de Vries H. An integrated approach for understanding health behavior; the I-change model as an example. *Psychol Behav Sci Int J*. 2017;2(2):555–85. <https://doi.org/10.19080/PBSIJ.2017.02.555585>.
41. Pyatak EA, Florindez D, Weigensberg MJ. Adherence decision making in the everyday lives of emerging adults with type 1 diabetes. *Patient Prefer Adherence*. 2013;7:709–18. <https://doi.org/10.2147/PPA.S47577>.
42. Sarbacker GB, Urteaga EM. Adherence to insulin therapy. *Diabetes Spectr*. 2016;29(3):166–70. <https://doi.org/10.2337/diaspect.29.3.166>.
43. Riaz M, Basit A, Fawwad A, et al. Factors associated with non-adherence to insulin in patients with type 1 diabetes. *Pak J Med Sci*. 2014;30(2):233–9.
44. Beck JK, Zhang Y, Shay CM, et al. Diabetes knowledge in young adults: associations with hemoglobin A1c. *Fam Syst Health*. 2015;33(1):28–35. <https://doi.org/10.1037/fsh0000101>.
45. Gillibrand R, Stevenson J. The extended health belief model applied to the experience of diabetes in young people. *Br J Health Psychol*. 2006;11(Pt 1):155–69. <https://doi.org/10.1348/135910705X39485>.
46. Wasserman R, Anderson BJ, Schwartz DD. Illness-specific risk-taking in adolescence: a missing piece of the nonadherence puzzle for youth with type 1 diabetes? *Diabetes Spectr*. 2017;30(1):3–10. <https://doi.org/10.2337/ds15-0060>.
47. De Weerd I, Visser AP, Kok G, van der Veen EA. Determinants of active self-care behaviour of insulin treated patients with diabetes: implications for diabetes education. *Soc Sci Med*. 1990;30(5):605–15. [https://doi.org/10.1016/0277-9536\(90\)90159-P](https://doi.org/10.1016/0277-9536(90)90159-P).
48. Berg CA, King PS, Butler JM, et al. Parental involvement and adolescents' diabetes management: the mediating role of self-efficacy and externalizing and internalizing behaviors. *J Pediatr Psychol*. 2011;36:329–39. <https://doi.org/10.1093/jpepsy/jsq088>.
49. Hilliard ME, Wu YP, Rausch J, et al. Predictors of deteriorations in diabetes management and control in adolescents with type 1 diabetes. *J Adolesc Health*. 2013;52(1):28–34. <https://doi.org/10.1016/j.jadohealth.2012.05.009>.
50. Monaghan M, Helgeson V, Wiebe D. Type 1 diabetes in young adulthood. *Curr Diabetes Rev*. 2015;11(4):239–50. <https://doi.org/10.2174/1573399811666150421114957>.
51. Helgeson VS. Young adults with type 1 diabetes: romantic relationships and implications for well-being. *Diabetes Spectr*. 2017;30(2):108–16. <https://doi.org/10.2337/ds16-0020>.
52. King KM, King PJ, Nayar R, Wilkes S. Perceptions of adolescent patients of the “lived experience” of type 1 diabetes. *Diabetes Spectr*. 2017;30(1):23–35. <https://doi.org/10.2337/ds15-0041>.
53. Lawson VL, Lyne PA, Harvey JN, et al. Understanding why people with type 1 diabetes do not attend for specialist advice: a qualitative analysis of the views of people with insulin-dependent diabetes who do not attend diabetes clinic. *J Health Psychol*. 2005;10:409–23. <https://doi.org/10.1177/1359105305051426>.
54. Harvey JN, Lawson VL. The importance of health belief models in determining self-care behaviour in diabetes. *Diabet Med*. 2009;26(1):5–13. <https://doi.org/10.1111/j.1464-5491.2008.02628.x>.
55. Polonsky WH, Fisher L. When does personalized feedback make a difference? a narrative review of recent findings and their implications for promoting better diabetes self-care. *Curr Diab Rep*. 2015;15(8):50–50. <https://doi.org/10.1007/s11892-015-0620-7>.

56. Åsa C, Siv S. Living with type 1 diabetes as experienced by young adults. *Nurs Open*. 2018;6(2):418–25. <https://doi.org/10.1002/nop2.222>.
57. Gürkan KP, Bahar Z. Living with diabetes: perceived barriers of adolescents. *J Nurs Res*. 2020;28(2):73. <https://doi.org/10.1097/jnr.0000000000000349>.
58. Sigurðardóttir ÁK. Self-care in diabetes: model of factors affecting self-care. *J Clin Nurs*. 2005;14(3):301–14. <https://doi.org/10.1111/j.1365-2702.2004.01043.x>.
59. Gherman A, Schnur J, Montgomery G, Sassu R, Veresiu I, David D. How are adherent people more likely to think? a meta-analysis of health beliefs and diabetes self-care. *Diabetes Educ*. 2011;37(3):392–408. <https://doi.org/10.1177/0145721711403012>.
60. Coyle ME, Francis K, Chapman Y. Self-management activities in diabetes care: a systematic review. *Aust Health Rev*. 2013;37(4):513–22. <https://doi.org/10.1071/AH13060>.
61. Nagasawa M, Smith MC, Barnes JH Jr, Fincham JE. Meta-analysis of correlates of diabetes patients' compliance with prescribed medications. *Diabetes Educ*. 1990;16(3):192–200. <https://doi.org/10.1177/014572179001600309>.
62. Robinson S, Newson RS, Liao B, Kennedy-Martin T, Battelino T. Missed and mistimed insulin doses in people with diabetes: a systematic literature review. *Diabetes Technol Ther*. 2021;23(12):844–56. <https://doi.org/10.1089/dia.2021.0164>.
63. Young V, Eiser C, Johnson B, et al. Eating problems in adolescents with type 1 diabetes: a systematic review with meta-analysis. *Diabet Med*. 2013;30(2):189–98. <https://doi.org/10.1111/j.14645491.2012.03771.x>.
64. Butler A, Hall H, Copnell B. A guide to writing a qualitative systematic review protocol to enhance evidence-based practice in nursing and health care. *Worldviews Evid Based*. 2016;13(3):241–9. <https://doi.org/10.1111/wvn.12134>.
65. Pollock A, Berge E. How to do a systematic review. *Int J Stroke*. 2018;13(2):138–56. <https://doi.org/10.1177/1747493017743796>.
66. Moher D, Shamseer L, Clarke M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Syst Rev*. 2015;4(1):1–1. <https://doi.org/10.1186/2046-4053-4-1>.
67. AlBurno H, Mercken L, Vries H, Al Mohannadi D, Jongen S, Schneider F. Extended Data Set: socio-cognitive determinants affecting insulin adherence/non-adherence in late adolescents and young adults with type 1 diabetes: a systematic review protocol. figshare. Dataset. 2021. <https://doi.org/10.6084/m9.figshare.15044151.v1>.
68. Viana LV, Gomes MB, Zajdenverg L, et al. Interventions to improve patients' compliance with therapies aimed at lowering glycated hemoglobin (HbA1c) in type 1 diabetes: systematic review and meta-analyses of randomized controlled clinical trials of psychological, telecare, and educational interventions. *Trials*. 2016;17:94–94. <https://doi.org/10.1186/s13063-016-1207-6>.
69. O'Hara MC, Hynes L, O'Donnell M, et al. A systematic review of interventions to improve outcomes for young adults with type 1 diabetes. *Diabet Med*. 2017;34(6):753–69. <https://doi.org/10.1111/dme>.
70. La Banca RO, de Cássia SP, Bueno M, et al. Strategies to educate young people with type 1 diabetes mellitus on insulin therapy: systematic review. *Texto e Contexto Enferm*. 2020;29: e2018033. <https://doi.org/10.1590/1980-265x-tce-2018-0338>.
71. Alhazami M, Pontinha VM, Patterson JA, Holdford DA. Medication adherence trajectories: a systematic literature review. *J Manag Care Spec Pharm*. 2020;26(9):1138–52. <https://doi.org/10.18553/jmcp.2020.26.9.1138>.
72. Bramer WM, Rethlefsen ML, Kleijnen J, Franco O. Optimal database combinations for literature searches in systematic reviews: a prospective exploratory study. *Syst Rev*. 2017;6(1):245–57. <https://doi.org/10.1186/s13643-017-0644-y>.
73. Beller EM, Chen JK-H, Wang UL-H, Glasziou PP. Are systematic reviews up-to-date at the time of publication? *Syst Rev*. 2013;2(1):1–6. <https://doi.org/10.1186/2046-4053-2-36>.
74. Cooper C, Booth A, Varley-Campbell J, et al. Defining the process to literature searching in systematic reviews: a literature review of guidance and supporting studies. *BMC Med Res Methodol*. 2018;18(1):85–99. <https://doi.org/10.1186/s12874-018-0545-3>.
75. Lefebvre C, Glanville J, Briscoe S, et al. Chapter 4: searching for and selecting studies. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA (editors). *Cochrane handbook for systematic reviews of interventions version 6.2* (updated February 2021). Cochrane, 2021. www.training.cochrane.org/handbook. Accessed 5 Mar 2021.
76. Petticrew M, Roberts H. *Systematic reviews in the social sciences: a practical guide*. Malden, MA: Blackwell Pub; 2006. <https://doi.org/10.1002/9780470754887>.
77. McSharry J, Byrne M, Casey B, et al. Behaviour change in diabetes: behavioural science advancements to support the use of theory. *Diabet Med*. 2020;37(3):455–63. <https://doi.org/10.1111/dme.14198>.
78. Horsley T, Dingwall O, Sampson M. Checking reference lists to find additional studies for systematic reviews. *Cochrane Database Syst Rev*. 2011;8:MR000026. <https://doi.org/10.1002/14651858.MR000026.pub2>.
79. Aromataris E, Riitano D. Systematic reviews: constructing a search strategy and searching for evidence. *Am J Nurs*. 2014;114(5):49–56. <https://doi.org/10.1097/01.NAJ.0000446779.99522.f6>.
80. Li L, Smith HE, Atun R, Tudor Car L. Search strategies to identify observational studies in MEDLINE and Embase. *Cochrane Database Syst Rev*. 2019;3(3):MR000041. <https://doi.org/10.1002/14651858.MR000041.pub2>.
81. McGowan J, Sampson M, Salzwedel DM, et al. Press peer review of electronic search strategies: 2015 guideline statement. *J Clin Epidemiol*. 2016;75:40–6. <https://doi.org/10.1016/j.jclinepi.2016.01.021>.
82. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *PloS Med*. 2021;18(3):1003583. <https://doi.org/10.1371/journal.pmed.1003583>.
83. Bramer WM, Giustini D, de Jonge GB, et al. De-duplication of database search results for systematic reviews in EndNote [published correction appears in *J Med Libr Assoc*. 2017 Jan; 105(1):111]. *J Med Libr Assoc*. 2016;104(3):240–3. <https://doi.org/10.3163/1536-5050.104.3.014>.
84. Porritt K, Gomersall J, Lockwood C. JBI's Systematic Reviews: study selection and critical appraisal. *Am J Nurs*. 2014;114(6):47–52. <https://doi.org/10.1097/01.NAJ.0000450430.97383.64>.
85. Moola S, Munn Z, Tufanaru C, et al. Chapter 7: systematic reviews of etiology and risk. In: Aromataris E, Munn Z (Editors). *JBI Manual for Evidence Synthesis*. JBI, 2020. Available from <https://synthesismanual.jbi.global>. <https://doi.org/10.46658/JBIMES-20-08>.

86. Ma LL, Wang YY, Yang ZH, et al. Methodological quality (risk of bias) assessment tools for primary and secondary medical studies: what are they and which is better? *Mil Med Res*. 2020;7(1):7–18. <https://doi.org/10.1186/s40779-020-00238-8>.
87. Cochrane Collaboration. *Cochrane Handbook for Systematic Reviews of Interventions*. (Higgins JPT, Green S, eds.). Chichester, England: Wiley-Blackwell; 2008. <https://doi.org/10.1002/9780470712184>.
88. Clifford S, Perez-Nieves M, Skalicky AM, et al. A systematic literature review of methodologies used to assess medication adherence in patients with diabetes. *Curr Med Res Opin*. 2014;30(6):1071–85. <https://doi.org/10.1185/03007995.2014.884491>.
89. Stolpe S, Kroes MA, Webb N, Wisniewski T. A systematic review of insulin adherence measures in patients with diabetes. *J Manag Care Spec Pharm*. 2016;22(11):1224–46. <https://doi.org/10.18553/jmcp.2016.22.11.1224>.
90. GRADEpro GDT: GRADEpro Guideline Development Tool [Software]. McMaster University, 2020 (developed by Evidence Prime, Inc.). <https://gradepro.org>. Accessed 2 Jan 2021.
91. Jaam M, Awaisu A, Ibrahim MI, Kheir N. Synthesizing and appraising the quality of the evidence on factors associated with medication adherence in diabetes: a systematic review of systematic reviews. *Value Health Reg Issues*. 2017;13:82–91. <https://doi.org/10.1016/j.vhri.2017.09.001>.
92. Kyngäs H. Compliance of adolescents with diabetes. *J Pediatr Nurs*. 2000;15(4):260–7. <https://doi.org/10.1053/jpdn.2000.6169>.
93. Lisy K. Quality counts: reporting appraisal and risk of bias. *JBIM Database Syst Rev Implement Rep*. 2015;13(3):1–2. <https://doi.org/10.11124/jbisrir-2015-2267>.

Extended data

Figshare: Extended Data Set: Socio-cognitive determinants affecting insulin adherence/non-adherence in late adolescents and young adults with type 1 diabetes: a systematic review protocol. pdf,

This systematic review contains the following extended data:

- Appendix 1: PubMed Search Strategy
- Appendix 2: JBI_Critical Appraisal_Quality Assessment Checklists

- Appendix 3: Data extraction tool

Reporting guidelines

Figshare: PRISMA-P checklist for ‘Socio-cognitive determinants affecting insulin adherence/non-adherence in late adolescents and young adults with type 1 diabetes: a systematic review protocol’, <https://doi.org/10.6084/m9.figshare.15044151>.

Data are available under the terms of the Creative Commons Zero "No rights reserved" data waiver (CC0 1.0 Public domain dedication).

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.