



REVIEWS

Measurement of Perceived Risk of Developing Diabetes Mellitus: A Systematic Literature Review

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ABSTRACT

BACKGROUND: This systematic review describes approaches to measuring perceived risk of developing type 2 diabetes among individuals without diagnoses and describes the use of theories, models, and frameworks in studies assessing perceived risk. While a systematic review has synthesized perceived risk of complications among individuals with diabetes, no reviews have systematically assessed how perceived risk is measured among those without a diagnosis.

METHODS: Medline, PubMed, PsycINFO, and CINAHAL databases were searched for studies conducted through October 2022 with measures of perceived risk among adults ≥ 18 years without a diabetes diagnosis. Extracted data included study characteristics, measures, and health behavior theories, models, or frameworks used.

RESULTS: Eighty-six studies met inclusion criteria. Six examined perceived risk scales' psychometric properties. Eighty measured perceived risk using (1) a single item; (2) a composite score from multiple items or subconstructs; and (3) multiple subconstructs but no composite score. Studies used items measuring "comparative risk," "absolute or lifetime risk," and "perceived risk" without defining how each differed. Sixty-four studies used cross-sectional designs. Twenty-eight studies mentioned use of health behavior theories in study design or selection of measures.

DISCUSSION: There was heterogeneity in how studies operationalized perceived risk; only one third of studies referenced a theory, model, or framework as guiding design or scale and item selection. Use of perceived lifetime risk, absolute risk, or comparative risk limits comparisons across studies. Consideration of context, target population, and how data are utilized is important when selecting measures; we present a series of questions to ask when selecting measures for use in research and clinical settings. This review is the first to categorize how perceived risk is measured in the diabetes prevention domain; most literature focuses on perceived risk among those with diabetes diagnoses. Limitations

include exclusion of non-English and gray literature and single reviewer screening and data extraction.

KEY WORDS: Perceived risk; Perceived susceptibility; Diabetes; Health behavior theory

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INTRODUCTION

Over 37 million US adults have type 2 diabetes, and an additional 96 million adults (36% of the US population)¹ have prediabetes and are at risk for progressing to type 2 diabetes. Although well-established, evidence-based interventions such as the Diabetes Prevention Program can delay or prevent type 2 diabetes,² enrollment and engagement in preventive programs are strongly influenced by risk perception.^{3,4} An individual's perceived risk of developing diabetes is their estimate of the probability that they will develop type 2 diabetes.^{3,4} It is a construct predictive of behavior change in multiple health behavior theories including the Health Belief Model, Protection Motivation Theory, and Theory of Reasoned Action.^{5–7} Improved understanding of perceived risk of developing diabetes, and the development of interventions accounting for individuals' perceived risk, may improve diabetes screening rates and enhance enrollment in, engagement with, and the impact of interventions such as the DPP.⁵

Simple, clinically relevant measures of perceived risk are critically important to engage patients in diabetes screening and to influence adoption of behaviors to prevent diabetes. However, perceived risk is a multifaceted theoretical construct that has been operationalized in multiple ways (Table 1), and the selection of measures often depends on researchers' or clinicians' goals, questions, and contexts. In addition, scale items and response options depend on how the construct is operationalized. For example, absolute risk is measured on a numerical scale, but individuals do not necessarily derive meaning from numerical risk

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Table 1 Risk-related Beliefs for Developing Diabetes

Construct Dimension	Conceptual definition	Example items
Perceived Risk ¹	Estimate of probability that one will develop diabetes at some point in the future	
<i>Absolute Risk</i>	Estimate of own risk without comparison to a reference group or standard ⁸	On a scale from 0–100, how likely are you to develop diabetes at some point in your life? (<i>numerical</i>) How likely are you to develop diabetes at some point in your life? (not at all likely – very likely; <i>verbal</i>)
<i>Comparative Risk</i>	Estimate of own risk compared to a reference group or standard ⁸	Compared to others of your same age and sex, how likely are you to develop diabetes at some point in your life? (less likely – more likely)
<i>Risk Affect/Worry</i>	Judgment of how at risk one feels, or how much one worries about the threat ^{18, 116}	To what extent do you worry about getting diabetes?
Perceived Severity	Perception of how serious getting diabetes would be	Getting diabetes would be a serious health problem
Personal Control	Belief that one's own behavior has an effect on the risk of developing diabetes	My personal efforts will help control my risk of getting diabetes

¹We use perceived risk to label this construct. Other terms, often used interchangeably in the literature, include susceptibility, vulnerability, or likelihood

estimates. Comparative risk assessments assess one's perceived chance of developing diabetes in contrast to a reference population.⁸ Comparative risk assessments, which may better capture an individual's intuitive sense of risk, are strongly associated with intentions to engage in health-promoting behaviors and behavior change.^{9–11}

In the diabetes literature, many have focused on the perceived risk of developing diabetes complications among those with diagnosed diabetes.¹² Fewer studies have examined perceived risk of developing diabetes among those without diagnosed diabetes. Further, systematic reviews have synthesized measurement and implementation of risk assessment tools that measure behavioral and anthropometric variables, but no systematic reviews have assessed measurement of attitudinal variables, such as perceived risk, among those without a diabetes diagnosis.^{13,14} With 1 in 3 US adults having prediabetes and at risk for developing type 2 diabetes,¹⁵ advancing measurement of the perceived risk of developing diabetes is critical to effective intervention for these individuals.

Therefore, the aims of this review are to describe approaches to measuring perceived risk of developing diabetes among those without diagnosed type 2 diabetes and to describe the use of guiding theories, models, and frameworks in studies assessing perceived risk.

METHODS

This review was conducted according to the Preferred Reporting Items of Systematic Reviews and Meta-Analyses guidelines.¹⁶ This review and a protocol for this review were not registered.

Eligibility Criteria

This review included studies published in English language peer-reviewed journals published up to the final search date (October 31, 2022). Eligible studies included those with a study population comprised of adult participants aged ≥ 18 years without a known type 2 diabetes diagnosis. Mixed-methods studies were included only if authors provided quantitative data to support qualitative findings.

Exclusion criteria were applied hierarchically: (1) review, commentary, protocol, or dissertation; (2) study population only < 18 years; (3) mixed < 18 year and ≥ 18 year old population with no ability to separate results; (4) participants include those with known type 2 diabetes, type 1 diabetes, or no ability to exclude results for participants with diabetes; (5) qualitative study; (6) no measurement of perceived risk of developing diabetes; and (7) no description of the perceived risk measure.

Information Sources and Search Strategies

Databases searched included Medline (Ovid), PubMed (Ovid), PsycINFO (Ovid), and CINAHL (EBSCO). A medical librarian assisted in developing the search strategy which included relevant search terms for perceived risk of developing diabetes. A combination of medical subject headings and keywords was used for the initial MEDLINE search and adapted for other databases. Finally, one reviewer searched the reference lists of all eligible studies for additional eligible studies.

Study Selection

References were downloaded to the bibliographic management program EndNote X8.2 and duplicates removed. Two reviewers (SAR, HHB) screened a random sample

of 66 titles and abstracts ($\kappa = 0.80$) to pilot test and refine screening criteria; disagreements about inclusion or exclusion were resolved through discussion and consultation with co-authors. The two reviewers were blind to journal titles, authors, and author affiliations. One reviewer then completed title and abstract screening and full text reviews independently.

Data Extraction and Analysis

One reviewer (HHB) extracted all data while a second reviewer (SAR) validated extracted data. Validation included a side-by-side comparison of each article and the table of extracted data. Data about each study included study aims, time period, study design, target population, number of participants, setting, country, and language. Data extracted about measurement of perceived risk included references for item(s) or instrument used, construct name/conceptual definition (e.g., absolute risk, comparative risk; see Table 1 for details), number of items, assignment of items to subconstruct, instructions for creating composite scores, reliability estimate, survey delivery method, and theory, model, or framework informing study design, scale selection, or item selection. All data elements were entered into a master table for analysis, which included summarizing elements across studies.

All items listed under a perceived risk heading were included as subconstructs. For example, if authors listed worry as a subconstruct of perceived risk, data related to those survey items were included. However, if study authors described worry as a construct separate and distinct from perceived risk under its own heading, data were not extracted and are not included in this review. Following Noble and colleagues¹³ systematic review of diabetes risk models and scores, this review does not rank order measures or recommend specific measures of perceived risk over others.

RESULTS

Study Selection

Five hundred and seventeen unique records were identified from the databases (Fig. 1). Eighty-six records met inclusion criteria following the two-step screening process. The three most frequent reasons for exclusion included participants with existing diagnosis of type 2 diabetes ($n = 250$), no measurement of perceived risk of developing diabetes ($n = 70$), and review, commentary, protocol, or dissertation ($n = 47$).

Study Characteristics

Six studies aimed to assess the psychometric properties of scales measuring perceived risk of developing diabetes,^{17–22} and 80 studies measured perceived risk within

broader research questions. Study designs included cross-sectional ($n = 64$),^{17–80} intervention ($n = 18$),^{81–98} and longitudinal ($n = 4$)^{99–102} designs (Table 2). The three most common settings included community settings ($n = 50$),^{17–21,24,25,27–29,33,35–37,40,42–47,51,52,55,58,59,61–65,68,71–78,81,83,88,90,92,96–99,101} outpatient clinics ($n = 20$),^{22,23,30,34,39,41,49,50,70,71,79,82–87,89,93,94} and universities ($n = 11$).^{21,38,48,53,54,56,57,60,67,69,102} The three most common countries where studies took place were the USA ($n = 57$),^{17–22,24–29,31–35,37–42,44,47–49,51–57,59,62–66,68,69,71,72,75,76,78,79,81,83,86,90,94,95,97,100,102} Netherlands ($n = 8$),^{23,30,36,43,85,89,92,101} and UK ($n = 6$).^{45,50,82,84,93,96} Among studies reporting survey delivery methods, the most common were web-based surveys ($n = 21$),^{18,19,21,28,34,38,41,43,44,47,48,51,54,59,62,65,67,78,83,86,102} in-person paper surveys ($n = 13$),^{17,20,24,26,27,32,37,39,44,50,53,55,89} and mailed surveys ($n = 9$).^{23,29,30,36,66,84,91,96,101} The number of study participants ranged from $N = 21$ ⁸⁹ to $N = 11,569$.⁷⁵

Studies Aimed at Evaluating the Scales' Psychometric Properties

Six studies aimed to evaluate the psychometric properties of scales measuring perceived risk of developing diabetes (Table 3). The scales included the Perception of Risk Factors of Type 2 Diabetes Mellitus (PRF-T2DM),^{19,21} Risk Perception Survey for Developing Diabetes (RPS-DD),²² Spanish-translated RPS-DD,¹⁷ Tripartite Model of Risk Perception (TRIRISK),¹⁸ and a 5-item unnamed scale to assess perceived susceptibility.²⁰

The RPS-DD,^{17,22} TRIRISK,¹⁸ and 5-item scale²⁰ used Likert-scale response options.^{21,19} RPS-DD items were not combined into an overall score; subscale reliability estimates for subconstructs ranged from $\alpha = 0.44$ ²² for optimistic bias to $\alpha = 0.88$ ¹⁷ for both comparative disease risk and comparative environmental risk. Reliability estimates for TRIRISK subscales ranged from $\alpha = 0.92$ for experiential risk perception to $\alpha = 0.96$ for both deliberative and affective risk perception.¹⁸ Reliability estimates for the 5-item perceived susceptibility scale were $\alpha = 0.71$ for perceived risk and $\alpha = 0.61$ the perceived severity.²⁰

The PRF-T2DM used 4-point ordinal response options (i.e., don't know, no risk, decreases risk, increases risk) to measure two subconstructs of perceived risk (personal, behavioral risk factors and environmental risk factors). Scores for both subconstructs were summed to create an overall perceived risk score. Overall reliability estimates for the PRF-T2DM ranged from $\alpha = 0.68$ ²¹ to $\alpha = 0.81$.¹⁹ No studies compared psychometric properties of the scales to others or describe additional aspects of validity (e.g., predicative validity).

The Health Belief Model guided scale development for the PRF-T2DM¹⁹ and the 5-item perceived susceptibility scale.²⁰ Other theoretical models cited included the Model

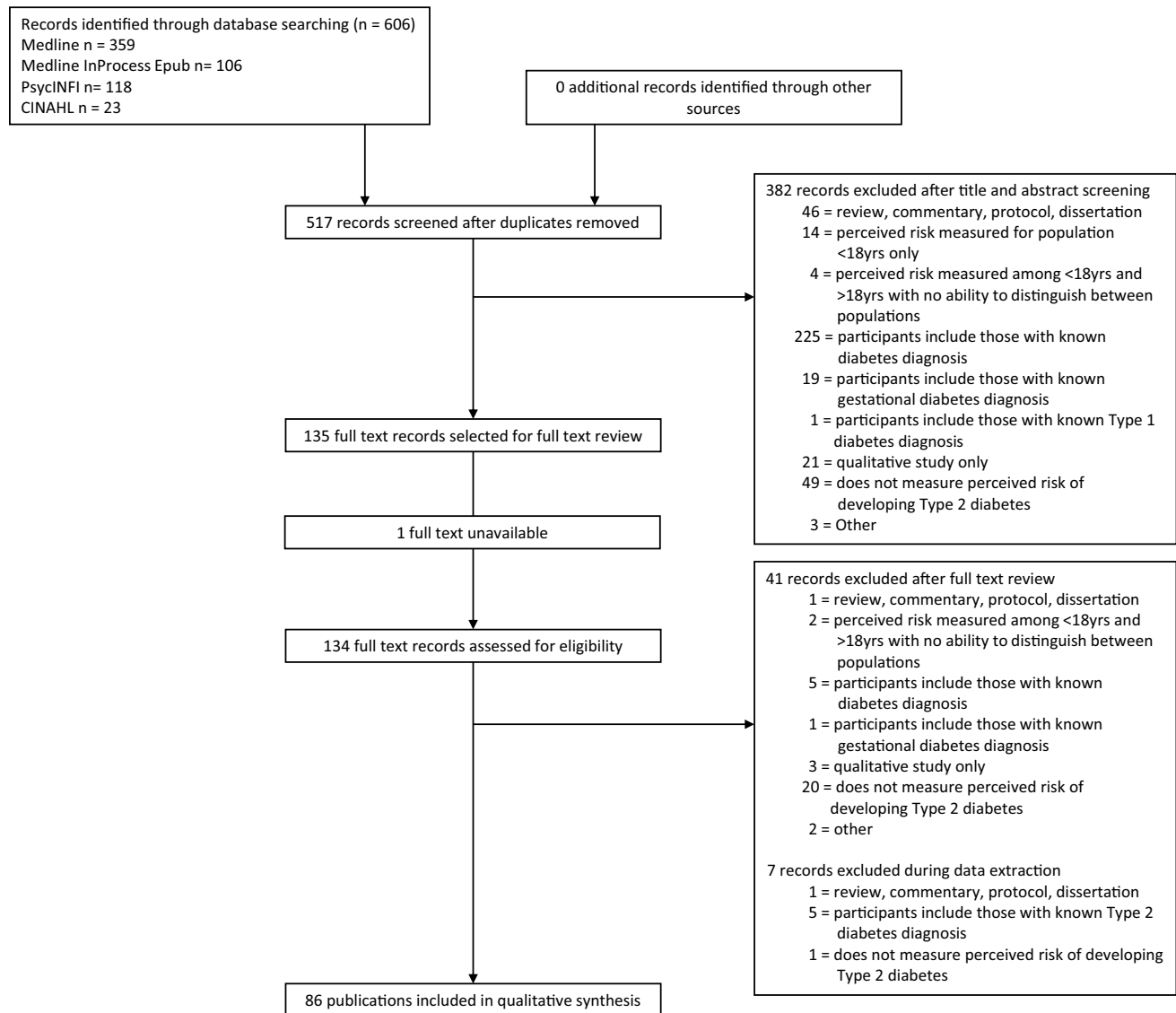


Figure 1 PRISMA Flowchart.

of Familial Risk Perception²¹ and the Tripartite Model of Risk Perception.¹⁸

Studies Measuring Perceived Risk Within Broader Research

Eighty studies measured perceived risk of developing diabetes within larger research studies. Measurement occurred in three distinct ways (Table 4): (1) as a single item ($n = 50$);^{24-27,31-34,39-44,49-52,55-59,64,67-71,73-76,79,81,82,86-88,90,91,93,95-102} (2) using a composite score from multiple items or subconstruct subscales ($n = 12$);^{29,35-37,46,53,54,63,72,77,80,85} and (3) using multiple subconstruct subscales but no composite score ($n = 18$).^{23,28,30,38,45,47,48,60-62,65,66,78,83,84,89,92,94}

Of studies reporting response options, the most common were Likert scales ($n = 56$)^{25,26,28,29,31-37,39-41,43-45,48,50,51,54,55,58-61,65-67,69-74,77-87,89-92,94,97-101} and 0 to 100 scales ($n = 1$

2).^{23,24,27,30,42,45,47,48,63,83,93,96} The most common Likert scale response option anchors were those indicating chance (no to high risk; $n = 21$),^{26,28,31,32,34,36,40,41,43,48,50,54,55,59,61,69,73,74,84-86} likelihood (not all to extremely likely; $n = 16$),^{36,39,44,45,65,67,78,81,82,85,87,90,91,95,97,100} and agreement (strongly disagree to strongly agree; $n = 10$).^{29,51,60,62,66,77,80,94,101}

Single Item. Fifty studies used a single item to measure perceived risk.^{24-27,31-34,39-44,49-52,55-59,64,67-71,73-76,79,81,82,86-88,90,91,93,95-102} Example items included assessment of general perceived risk (e.g., Do you feel you could be at risk for diabetes or prediabetes? Dichotomous response option: Yes, No);⁶⁸ absolute perceived risk (e.g., On a scale from 0 to 100, how likely are you to get type 2 diabetes in your lifetime? 7-point Likert scale response option: extremely unlikely to almost certain);⁶⁷ comparative perceived risk (e.g., What are the changes

Table 2 Characteristics of Studies Assessing Perceived Risk of Developing Diabetes in Individuals Without a Diabetes Diagnosis (N = 86)

Author (year)	Study design	Survey delivery	Inclusion criteria	Study N	Setting	Country	Language
Cross-sectional studies Adriaanse (2003)	Cross-sectional	Mail survey	Adults 50–75 years, at low or high risk for diabetes, participating in a population-screening program	7736	Outpatient	Netherlands	–
Montgomery (2003)	Cross-sectional	In-person paper-based survey	Adults with no history of breast, prostate, or colon cancers, or heart disease	522	Hospital, Community	USA	–
Walker (2003)	Cross-sectional	In-person paper-based survey	Physicians without a diabetes diagnosis attending conferences	535	Conference	Canada, USA	–
Kemple (2005)	Cross-sectional	Telephone survey	Adults in Oregon ≥ 45 years, self-reported overweight by BMI	1831	Community	USA	–
DiLorenzo (2006)	Cross-sectional	In-person paper-based survey	Adults with no history of breast, prostate, or colon cancers, or heart disease	434	Hospital, community	USA	–
Johnson (2006)	Cross-sectional	Web-based survey	Adults ≥ 45 years	582	Community	USA	–
Blue (2007)	Cross-sectional	Mail survey	Adults ≥ 21 years, at risk for diabetes by the ADA criteria, English-speaking	106	Community	USA	English
Adriaanse (2008)	Cross-sectional	Mail survey	Adults 50–75 years, at low or high risk for diabetes	7736	Outpatient	Netherlands	–
Hivert (2009)	Cross-sectional	In-person survey	Primary care clinic patients without CVD	150	Outpatient	USA	–
Pinelli (2009)	Cross-sectional	In-person paper-based survey	Pharmacists attending conference self-reporting no known diabetes diagnosis	218	Conference	USA	–
Zlot (2009)	Cross-sectional	Telephone survey	Adults in Oregon ≥ 18 years, noninstitutionalized	6039	Community	USA	–
Acheson (2010)	Cross-sectional	Web-based survey	Non-pregnant adults 35–65 years, not diagnosed with CHD, stroke, or cancer	2330	Outpatient	USA	English
Pinelli (2010)	Cross-sectional	Verbally administered in-person	Self-identified Arab-Americans ≥ 30 years with BMI ≥ 27 kg/m ²	116	Community	USA	–
Sousa (2010)	Cross-sectional	Web-based survey	Adults ≥ 21 years, can understand, speak, and write English	629	Community	USA	–
Claassen (2011)	Cross-sectional	Mail survey	Adults 57–79 years, previously screened positive for high DM risk	255	Community	Netherlands	–
Della (2011)	Cross-sectional	In-person paper-based survey	Adults 25–55 years, at risk for diabetes by the ADA criteria	168	Community	USA	English
Dartlow (2012)	Cross-sectional	In-person paper-based survey	Females ≥ 18 years, self-reported overweight or obese, can read English or Spanish	397	Outpatient	USA	English, Spanish

Table 2 (Continued)

Author (year)	Study design	Survey delivery	Inclusion criteria	Study N	Setting	Country Language
Diaz (2012)	Cross-sectional	In-person survey	Adults \geq 18 years self-identifying as Hispanic/Latino	183	Community	USA
Dickerson (2012)	Cross-sectional	Web-based survey	College students not diagnosed with cancer or heart disease	612	University	USA
Dorman (2012)	Cross-sectional	Web-based survey	Adults 35–65 years, participants from the FHI/Tr, no history of CHD, stroke, breast, colon, or ovarian cancers	3344	Outpatient	USA
Siaki (2012)	Cross-sectional	Structured interview	Adult Samoans who are obese and self-report having 1 other component of metabolic syndrome (i.e., HTN, elevated blood glucose level, or dyslipidemia)	43	Community	USA English, Samoan
Della (2013)	Cross-sectional	In-person paper-based survey	Adults 25–55 years, at risk for diabetes by the ADA criteria	168	Community	USA
Wijdenes (2013)	Cross-sectional	Web-based survey	Adults 35–65 years, \geq 1 first-degree relative with diabetes; BMI \geq 25 kg/m ² , can read Dutch, does not identify as being Hindustani, Turkish, Creolish, or Moroccan	1120	Community	Netherlands Dutch
de Groot (2014)	Cross-sectional	Web-based or in-person paper-based survey	Adults 18–65 years, literate in English or Spanish, BMI $>$ 15 kg/m ²	265	Community	USA English, Spanish
Godino (2014)	Cross-sectional	Self-report survey	General practice patients born between 1950 and 1975, without a terminal illness with a prognosis of less than 1 year, a psychotic illness, being pregnant or lactating, or being unable to walk unaided	569	Community	U.K
Kolb (2014)	Cross-sectional	Self-report survey	Adults with prediabetes (defined as A1C of 5.7–6.4% (40–48 mmol/mol) or a fasting glucose of 100–125), never prescribed a diabetic medication, English-speaking, able to walk, with email access	54	Outpatient	USA English
Lavielle (2014)	Cross-sectional	Semi-structured interview	Adults \geq 18 years, living within sampled census tracts	800	Community	Mexico
Winter (2014)	Cross-sectional	Web-based survey	Obese adults 50–62 years participating in the American Life Panel (ALP)	836	Community	USA
Amuta (2015)	Cross-sectional	Web-based survey	Undergraduate students \geq 18 years, overweight or obese	319	University	USA

Table 2 (Continued)

Author (year)	Study design	Survey delivery	Inclusion criteria	Study N	Setting	Country Language
Guess (2015)	Cross-sectional	In-person paper-based survey	General practice patients at high risk for type 2 diabetes (BMI 25–35 kg/m ² , with a reported fasting plasma glucose in the previous 18 months of 5.6–6.9 mmol/L)	59	Outpatient	U.K
Fukuoka (2015)	Cross-sectional	Web-based and in-person surveys	Self-identified Caucasian, Filipino, Korean, or Latinos	904	Community	USA
Piccinino (2015)	Cross-sectional	Computer-assisted telephone surveys	Adults ≥ 35 years, civilian, noninstitutionalized, living in households with landline telephones	6075	Community	USA
Reyes-Velazquez (2015)	Cross-sectional	In-person paper-based survey	University students	652	University	USA
Basilio (2016)	Cross-sectional	Web-based survey	European- or Latino-American, undergraduate students	235	University	USA
Ferrer (2016)	Cross-sectional	Web-based survey	Participants with US IP addresses using mTurk (Amazon survey platform)	447	Community	USA
Joiner (2016a)	Cross-sectional	In-person paper-based survey	Adults ≥ 20 years, foreign-born living in the USA, speak predominantly Spanish at home	146	Community	USA
Joiner (2016b)	Cross-sectional	In-person paper-based survey	Non-pregnant, Latino adults ≥ 20 years, foreign-born living in the USA, speak predominantly Spanish at home	146	Community	USA
Mongiello (2016a)	Cross-sectional	Self-report survey	City University of New York students with ≥ 3 known risk factors for diabetes	1579	University	USA English
Mongiello (2016b)	Cross-sectional	Self-report survey	City University of New York students with ≥ 3 known risk factors for diabetes	1579	University	USA English
Shah (2016)	Cross-sectional	Web-based survey	Adults 18–60 years, positive family history of DM	248	Community, University	USA
Vornanen (2016)	Cross-sectional	Self-report survey	Finnish adults 25–74 years, from the National FINRISK 2007 Survey	6258	Community	Finland
Chopra (2017)	Cross-sectional	Web-based survey	Adults 21–50 years, Appalachian women residing in West Virginia	202	Community	USA
Kharono (2017)	Cross-sectional	Self-report survey	University medical students ≥ 18 years	378	University	Uganda English
Kowall (2017)	Cross-sectional	In-person interview	Adults 25–74 years, who were regional residents and participants in the S4 baseline study and the 14-year follow-up FF4 study	2186	Community	Germany

Table 2 (Continued)

Author (year)	Study design	Survey delivery	Inclusion criteria	Study N	Setting	Country Language
Simonds (2017)	Cross-sectional	In-person survey	Self-identified local tribe members of the Northern Plains Tribe, > 18 years	143	Community	USA
Wilkie (2017)	Cross-sectional	Telephone survey	NHANES respondents from sampling years who were age 18 and older, were examined in the Mobile Examination Center, had never previously been told they have T2DM	3238	Community	USA English, Spanish
Orom (2018)	Cross-sectional	Web-based survey	Adults ≥ 18	1005	Community	USA
Paige (2018)	Cross-sectional	Web-based survey	Adults ≥ 18 years, residing in a rural county, with English language proficiency	252	Community	USA
Shaak (2018)	Cross-sectional	Mail survey	Patient with ≥ 1 visit in past year at one of four urban primary care practices, 18–65 years, documented Hispanic ethnicity, ICD-10 diagnosis code of impaired fasting glucose and/or prediabetes, HbA1c value between 5.7 and 6.4% in the past year	120	Hospital	USA English, Spanish
Skot (2018)	Cross-sectional	Web-based survey	Undergraduate and post-graduate students < 40 years attending one of five major universities in Denmark, had ≥ 3 months left on their study program	1205	University	Denmark English, Danish
Yang (2018)	Cross-sectional	In-person survey	Adults ≥ 20 years, no self-identified “other” race	10,999	Community	USA
Agarwal (2019)	Cross-sectional	n/a	Adults ≥ 50 years not participating in Community Parapharmaceutical Clinic program	28	Outpatient	Canada
Calhoun (2019)	Cross-sectional	In-person and remote surveys	Adults 18–81 years, no self-reported history of diabetes, not currently pregnant	409	Outpatient	USA
Daack-Hirsch (2019)	Cross-sectional	In-person survey	Adults 18–60 years, positive family history of diabetes	109	Community; clinic; outpatient	USA
Guo (2019)	Cross-sectional	Self-administered survey	Mothers of ≥ 1 child aged 3–5 years and/or child could attend preschool activities	222	Community	China Chinese
Heidemann (2019)	Cross-sectional	Telephone survey	Adults ≥ 18 years, German-speaking	2327	Community	Germany German
Hsueh (2019)	Cross-sectional	Computer-assisted in-person survey	Adults ≥ 18 years, no prediabetes diagnosis	11,569	Community	USA
Mirzaei-Alavije (2019)	Cross-sectional	Self-administered survey	Adults > 30 years referred to health centers in Kermanshah City, Iran	162	Clinic	Iran

Table 2 (Continued)

Author (year)	Study design	Survey delivery	Inclusion criteria	Study N	Setting	Country Language
Murillo (2019)	Cross-sectional	Computer-assisted in-person survey	Adults ≥ 18 years, no prediabetes diagnosis	9550	Community	USA
Pelullo (2019)	Cross-sectional	Self-administered survey	Parents of students attending primary, middle, and high schools located in the Naples metropolitan area	527	Community	Italy Italian
Riley (2019)	Cross-sectional	Web-based survey	Adults ≥ 18 years, no diagnosis colon cancer, ability to communicate in English	1005	Community	USA English
Abshire (2020)	Cross-sectional	In-person survey	Students 18–25 years, college-enrolled, self-reported lifelong resident of rural or urban areas	116	University	USA
Daack-Hirsch (2020)	Cross-sectional	In-person and telephone survey	Adults 18–60 years, positive family history of diabetes, non-Hispanic White, non-Hispanic Black, Hispanic	153	Community	USA
Rochefort (2020)	Cross-sectional	Telephone survey	Adults ≥ 18 –65, primary care patients, ≥ 1 primary care visit with integrated, safety-net health system, no pregnancy in previous 2 years, no prediabetes diagnosis, no resulted fasting glucose or A1C test in the diabetes or prediabetes range in previous 2 years	641	Outpatient	USA English, Spanish
Intervention studies Polley (1997)	Intervention	Self-report survey	Adults 40–55 years, negative 2-h OGTT, 30–100% overweight (based on 1983 Metropolitan Life Insurance tables), family history of DM (≥ 1 parent with NIDDM), without health problems or limitations to participating in a regular walking program	154	Community	USA
Pierce (2000)	Intervention	Structured interview	Adults ≥ 18 years, living in south London, with 1 parent diagnosed with diabetes who is a general practice patient	105	Outpatient	U.K.
Harle (2008)	Intervention	Web-based survey	Adults ≥ 45 years	100	Community	USA
Paddison (2009)	Intervention	Mail survey	Primary care adult patients 40–69 years, diabetes screening participants identified as high risk for having undiagnosed diabetes, participants in the ADDITION trial and substudy	5334	Outpatient	U.K.

Table 2 (Continued)

Author (year)	Study design	Survey delivery	Inclusion criteria	Study N	Setting	Country Language
Pijl (2009)	Intervention	In-person survey	Adults ≤ 75 years who participated in a diabetes screening program 5 years prior, self-reported family history (one or more first-degree relatives), scored highest diabetes risk on a symptom-risk questionnaire, and understand Dutch	118	Outpatient	Netherlands
Wang (2009)	Intervention	Web-based survey	Adults 35–65 years, participants from the FHIIt, no history of CHD, stroke, breast, colon, or ovarian cancers	2362	Outpatient	USA
Messier (2010)	Intervention	Self-report survey	Women, BMI ≥ 27 kg/m ² , no menstruation for ≥ 1 year and FSH ≥ 30 , no history or evidence of inflammatory disease, CVD, PVD, stroke, diabetes, or medications affecting cardiovascular function and/or metabolism	137	Community	Canada
Bassett (2011)	Intervention	Telephone survey	Subset of participants in the SHAPE-SCI (spinal cord injury) study who completed objective health-risk testing	62	Outpatient	Canada
Heideman (2012)	Intervention	In-person paper-based survey	Adults 25–55 years, overweight (BMI ≥ 25 kg/m ²), with first degree relative(s) with T2DM	21	Outpatient	Netherlands
Hovick (2014)	Intervention	At-home survey	Mexican-American households with ≥ 3 adults, ≥ 2 generations, ≥ 2 related biologically, ≥ 1 adult was a spouse/partner	497	Community	USA English, Spanish
Nishigaki (2014)	Intervention	In-person survey, mail survey	Adults 30–60 years, with ≥ 1 first-degree relative with T2DM, no diagnosis of metabolic syndrome	216	Worksite	Japan
Vlaar (2015)	Intervention	In-person verbally administered survey	Non-pregnant South Asian (Hindustani Surinamese) adults 18–60 years, initially screened at high risk of diabetes	535	Community	Netherlands
Godino (2016)	Intervention	Self-report survey	Adults 36–61 years, general practice patients, no history of terminal illness with a prognosis of less than one year, a psychotic illness, being pregnant or lactating, or being unable to walk unaided	569	Outpatient	U.K.

Table 2 (Continued)

Author (year)	Study design	Survey delivery	Inclusion criteria	Study N	Setting	Country	Language
Wu (2017)	Intervention	In-person survey	Non-pregnant, adults 18–81 years, with no prior genetic testing for diabetes, with FBG <7 mmol/L (<126 mg/dL) at enrollment	391	Outpatient	USA	—
Brawarsky (2018)	Intervention	Self-administered survey	Adult primary care patients receiving care within the primary care research network	4703	Health system	USA	—
Silarova (2018)	Intervention	Mail survey	Adults 36–61 years, general practice patients with sufficient data to calculate genetic and phenotypic risk of T2D, no history of terminal illness with a prognosis of less than one year, a psychotic illness, being pregnant or lactating, or being unable to walk unaided	379	Community	U.K	—
Fukuoka (2022)	Intervention	In-person survey	Adults ≥ 18 years, BMI ≥ 25 kg/m ² , self-identify as Hispanic, smartphone/app users, no diabetes diagnoses, ability to participate in exercise/diet program	69	Community	USA	—
Halmesvaara (2022)	Intervention	Self-administered survey	Adults ≥ 18 years, no type 2 diabetes diagnosis participating in National FinHealth Study 2017	3177	Community	Finland	—
Longitudinal studies Willems (2014)	Longitudinal	Mail survey	Adults 40–75 years, waist circumference ≥ 80 cm for females and ≥ 94 cm for males	1487	Community	Netherlands	—
Kullgren (2016)	Longitudinal	Web-based survey, semi-structured telephone interview	University employees who screened positive for pre-diabetes	82	University	USA	—
McPhee (2020)	Longitudinal	Telephone survey	Adults with cerebral palsy	31	N/A	USA	—
Vornanen (2021)	Longitudinal	Self-administered survey	Adults 45–74 years	909	Community	Finland	—

Table 3 Studies Assessing the Psychometric Properties of Scales Measuring Perceived Risk of Developing Diabetes (n = 6)

Author (year)	Construct ^a Subconstruct	# items (α)	Response options ^b Scoring	Source(s) for scale/item(s)	Guiding theory, model, or framework
Sousa (2010)	Perceived risk: -Personal, behavioral risk factors -Environmental risk factors	12 (0.81) 6 (0.74) 6 (0.80)	All: 4-point ordinal scales: don't know, no effect, decreases risk, increases risk <i>Sum of all items</i>	Janz (1984); ¹¹⁸ American Diabetes Association [ADA] (2008a); ¹¹⁹ CDC (2007); ¹²⁰ ADA (2008b); ¹²¹ Gavin (2002); ¹²² Elbein (1997); ¹²³ Ambrose (2001) ¹²⁴	Health Belief Model
Della (2013)	Perceived risk Perceived severity	5 (0.71) 4 (0.61)	All: 5-point Likert scales: disagree a lot to agree a lot <i>Mean of items for each construct; not combined</i>	Nijhof (2008) ¹²⁵	Health Belief Model
Ferrer (2016)	Perceived risk -Deliberative risk -Affective risk -Experiential risk	6 (0.96) 6 (0.96) 6 (0.92)	Scale 0–100 and 7-point Likert scales: likely to unlikely; very low to very high; SD to SA; much lower to much higher 7-point Likert scales: not at all to extremely 7-point Likert scales: not at all to extremely; SD to SA <i>Not specified</i>	HINTS; Dillard (2012); ¹¹ Weinstein 2007); ¹¹⁶ Janssen (2011); ¹²⁶ Janssen (2014); ¹²⁷ Klein (2011) ¹²⁸	Tripartite Model of Risk Perception
Joiner (2016a)	Perceived risk -Optimistic bias -Personal control -Worry -Comparative disease risk -Comparative environmental risk -Diabetes risk knowledge	2 (0.72) 2 (0.67) 2 (0.54) 15 (0.88) 9 (0.88) 11	4-point Likert scales: SA to SD 4-point Likert scales: SA to SD 4-point Likert scales: SA to SD 4-point Likert scale: no risk to high risk 4-point Likert scale: no risk to high risk 3-point ordinal: Increases risk, has no effect, decreases risk <i>Mean of items for each subscale, except risk knowledge; Sum of diabetes risk knowledge items</i>	RPS-DD ²⁶	–
Shah (2016)	Perceived risk -Personal, behavioral risk factors -Environmental risk factors	12 (0.68) 6 (0.60) 6 (0.67)	All: 4-point ordinal scales: don't know, no effect on risk, decreases risk, increases risk <i>Sum of all items</i>	Revised Self-Care Agency Scale Sousa (2010) ¹²⁹	Familial Risk Perception Model
Rochefort (2020)	Perceived risk -Optimistic bias -Personal control -Worry	8 (0.44) 2 (0.44) 4 (0.71) 2 (0.53)	All: 4-point Likert scales: SA to SD <i>Mean of items for each subscale</i>	RPS-DD ²⁶	–

^aWe used authors' labels for constructs and subconstructs

^bSA strongly agree, SD strongly disagree

of you getting diabetes compared to an average man/woman your age? 7-point Likert scale: a lot lower to a lot higher);⁴³ and lifetime perceived risk (e.g., How likely are you to get diabetes in your lifetime? 4-point Likert scale response option: not likely to definitely).⁹⁰

Eight studies referenced the RPS-DD as the source for their measurement; all used the single comparative risk item to measure perceived risk.^{31,32,50,51,56,73}

Three measured the remaining constructs of the RPS-DD as either covariates³² or to understand the nuances of participants' risk perceptions.^{50,73} Fifteen studies cited at least one guiding theory, model, or framework.^{40,41,44,49,57,64,69–71,79,81,88,91,96,100} The Health Belief Model was the most commonly cited theory (n = 10).^{40,41,44,57,69,70,81,88,91} One study tested its own conceptual model, but did not name a guiding theory.²⁷

Table 4 Studies Measuring Perceived Risk of Developing Diabetes Within Broader Studies (n = 80)

Author (year)	Construct ^a Subconstruct	# items (α)	Response options ^b Scoring	Source(s) for scale/item(s)	Guiding theory, model, or framework
Single item Polley (1997)	Perceived risk	1	5-point Likert scale: extremely unlikely to extremely likely	Melamed (1996); ¹³⁰ Ransford (1996) ¹³¹	Health Belief Model, Protection Motivation Theory
Pierce (2000)	Perceived risk	1	4-point Likert scale: very likely to not at all likely	—	—
Montgomery (2003)	Comparative per- ceived risk	1	Scale 0–100: not at all likely to extremely likely	—	—
Walker (2003)	Perceived risk	1	4-point Likert scale: almost no risk to high risk	—	—
Kemple (2005)	Perceived risk affect	1	4-point Likert scale: very worried to not at all worried	Oregon BRFSS ¹³²	—
DiLorenzo (2006)	Perceived lifetime risk	1	Scale 0–100%: not at all likely to extremely likely	—	Testing own conceptual model
Hivert (2009)	Perceived risk	1	4-point Likert scale: no risk to high risk	RPS-DD ²⁶	—
Pinelli (2009)	Perceived risk	1	4-point Likert scale: no risk to high risk	RPS-DD ²⁶	—
Wang (2009)	Comparative per- ceived risk	1	5-point Likert scale: much lower than average to much higher than average	Weinstein (1980); ¹³³ Weinstein (1982); ¹³⁴ Woloshin (1999) ¹³⁵	—
Zlot (2009)	Perceived risk affect	1	4-point Likert scale: very worried to not at all worried	Oregon BRFSS ¹³⁶	—
Acheson (2010)	Comparative per- ceived risk	1	5-point Likert scale: much lower than average to much higher than average	Weinstein (1980); ¹³³ Weinstein (1982) ¹³⁴	—
Messier (2010)	Perceived risk	1	4-point scale: n/a	Janz (2002) ¹³⁷	Health Belief Model
Bassett (2011)	Absolute perceived risk	1	7-point Likert scale: very unlikely to very likely	Weinsten (1994); ¹³⁸ Milne (2002) ¹³⁹	—
Darlow (2012)	Comparative per- ceived risk	1	5-point Likert scale: a lot less likely to a lot more likely	—	—
Diaz (2012)	Perceived risk	1	4-point Likert scale: almost no risk to high risk	RPS-DM ¹⁴⁰	Health Belief Model
Dorman (2012)	Comparative Per- ceived risk	1	5-point Likert scale: much lower than average to much higher than average	—	Health Belief Model, Theory of Planned Behavior
Siaki (2012)	Perceived lifetime risk	1	Scale 0–100, 10-point increments: low to high	Brewer (2004); ¹¹² Christian (2005) ¹⁴¹	—
Wijdenes (2013)	Comparative per- ceived risk	1	7-point Likert scale: a lot lower to a lot higher	—	—
de Groot (2014)	Perceived risk	1	5-point Likert scale: likely to unlikely	—	Health Belief Model, Theory of Planned Behavior and Rea- soned Action, Social Cognitive Theory, Transactional Model of Stress and Coping, Precaution Adoption Process Model
Hovick (2014)	Perceived lifetime risk	1	4-point Likert scale: not likely to defi- nitely	—	—
Kolb (2014)	Comparative per- ceived risk	1	n/a	Weymiller (2007); ¹⁴² Walker (2007) ¹⁴⁰	Transtheoretical model

Table 4 (continued)

Author (year)	Construct ^a Subconstruct	# items (α)	Response options ^b Scoring	Source(s) for scale/item(s)	Guiding theory, model, or framework
Nishigaki (2014)	Perceived risk	1	5-point Likert scale: very unlikely to very likely	–	Health Belief Model
Willems (2014)	Perceived risk	1	4-point Likert scale: SD to SA	Symptom Risk Questionnaire ¹⁴³	–
Fukuoka (2015)	Comparative per- ceived risk	1	4-point Likert scale: SA to SD	RPS-DD ²⁶	–
Guess (2015)	Perceived risk	1	4-point Likert scales: no risk to high risk	RPS-DD ²⁶	–
Piccinino (2015)	Perceived risk	1	n/a	–	–
Godino (2016)	Perceived lifetime risk	1	Scale 0–100: certain not to happen to certain to happen	–	–
Joiner (2016b)	Perceived risk	1	4-point Likert scale: almost no risk to high risk	RPS-DD ²⁶	–
Kullgren (2016)	Perceived risk	1	n/a	Adriaanse (2003); ²³ Adriaanse (2008) ³⁰	–
Mongiello (2016a)	Comparative per- ceived risk	1	n/a	RPS-DD ²⁶	–
Mongiello (2016b)	Comparative per- ceived risk	1	n/a	Clarke (2000) ¹⁴⁴	Health Belief Model
Vornanen (2016)	Perceived lifetime risk	1	5-point Likert scale: I have diabetes, very low to very high	Finish National FIN- RISK Survey	–
Chopra (2017)	Comparative per- ceived risk	1	5-point Likert scale: much lower than general population to much higher than general population	HINTS ¹⁴⁵	–
Wilkie (2017)	Perceived risk	1	n/a	NHANES	Andersen's Behavioral Model
Brawarsky (2018)	Comparative risk	1	3-point scale: more likely, less likely, about as likely to get	–	–
Silarova (2018)	Perceived lifetime risk	1	Scale 0–100: certain not to happen to certain to happen	Diefenbach (1993) ¹⁴⁶	Protection Motivation Theory; Common Sense Model
Skøt (2018)	Perceived lifetime risk	1	7-point Likert scale: extremely unlikely to almost certain	–	–
Yang (2018)	Perceived risk	1	Dichotomous: Yes, no	–	–
Abshire (2019)	Perceived risk	1	5-point Likert scale: very low to very high	–	Health Belief Model
Agarwal (2019)	Perceived risk affect	1	7-point Likert scale: not at all concerned to extremely con- cerned	Health Belief Model Scale, ¹⁴⁷ Brief Illness Perception Questionnaire ¹⁴⁸	Health Belief Model
Calhoun (2019)	Perceived risk	1	5-point Likert scale: definitely will get to definitely will not get diabetes	Brief Illness Percep- tion Questionnaire ¹⁴⁸	Health Belief Model
Daack-Hirsch (2019)	Perceived risk affect	1	5-point Likert scale: Never to almost every day	–	Familial risk perception personalization model
Guo (2019)	Perceived risk	1	4-point Likert scale: no risk to high risk	RPS-DD ²⁶	–
Heidemann (2019)	Perceived risk	1	4-point Likert scale: almost no risk to high risk	Kim (2007) ¹⁴⁹	–
Hsueh (2019)	Perceived risk	1	Categorical: Yes, no, I don't know	NHANES	–
Murillo (2019)	Perceived risk	1	Dichotomous: Yes, no	NHANES	–
McPhee (2020)	Perceived risk	1	7-point Likert scale: very unlikely to very likely	Bassett (2011) ⁸⁷	Protection Motivation Theory

Table 4 (continued)

Author (year)	Construct ^a Subconstruct	# items (α)	Response options ^b Scoring	Source(s) for scale/item(s)	Guiding theory, model, or framework
Vornanen (2021)	Perceived absolute lifetime risk	1	5-point Likert scale: very low to very high	Godino (2014) ¹⁵⁰	–
Fukuoka (2022)	Comparative perceived risk	1	5-point Likert scale: much less likely to much more likely	–	–
Halmesvaara (2022)	Perceived risk	1	5-point Likert scale: very small to very large	–	–
Multiple items, composite score					
Blue (2007)	Perceived risk	3		Champion (1999) ¹⁵¹	Theory of Planned Behavior
	- Likelihood	1	5-point Likert scale: SA to SD		
	- Risk in next few years	1	5-point Likert scale: SA to SD		
	- Lifetime risk	1	5-point Likert scale: SA to SD		
<i>Not specified</i>					
Pijl (2009)	Perceived risk	3 (0.88)		Alssema (2008) ¹⁵²	–
	- 5-year risk	1	7-point Likert scales: very likely to very unlikely		
	- Based on feelings, chances of developing in 5 years	1	7-point Likert scale: very low to very high		
	Comparative risk	1	7-point Likert scale: a low lower to a lot higher		
<i>Mean of items</i>					
Pinelli (2010)	Perceived risk		All: 4-point Likert scales: n/a	RPS-DD ²⁶	–
	- Comparative disease risk	15	<i>Not specified</i>		
	- Environmental risk	9			
	- Optimistic bias	2			
	- Personal control	4			
	- Worry	2		Symptom Risk Questionnaire ¹⁴³	–
Claassen (2011)	Perceived risk	2 ($r=0.93$)	7-point Likert scales: very unlikely to very likely		
	- 10-year risk		7-point Likert scale: very low to very high		
	- Based on feelings, chances of developing in 10 years				
<i>Mean of items</i>					
Della (2011)	Perceived risk	6 (0.70)	5-point Likert scale: disagree a lot to agree a lot	Nijhof (2008) ¹²⁵	Health Belief Model
<i>Mean of items</i>					
Lavielle (2014)	Perceived risk	2		Weinsten (2000); ¹⁵³ Aggleton (1994) ¹⁵⁴	–
	- Likelihood	1	Visual analog scale 1–10: not at all likely to likely		
	- Severity	1	Visual analog scale 1–10: not at all serious to serious		
<i>Sum of items</i>					
Reyes –Velazquez (2015)	Perceived lifetime risk	3 (0.80)	4-point ordinal: great risk, some risk, not sure, no risk	Covello (2002) ¹⁵⁵	–
	- Based on lifestyle		3-point Likert: very concerned to not concerned at all		

Table 4 (continued)

Author (year)	Construct ^a Subconstruct	# items (α)	Response options ^b Scoring	Source(s) for scale/item(s)	Guiding theory, model, or framework
Not specified Basilio (2016)	- Based on family background - Concern	4-point ordinal: great risk, some risk, not sure, no risk			
	Perceived risk	2 (0.95)		Aiken (1995); ¹⁵⁶ Dolan (1997); ¹⁵⁷ Gerend (2004) ¹⁵⁸	–
Mean of items Simonds (2017)	- Chances of diabetes - Susceptibility		6-point Likert scale: very low chance to very high chance 6-point Likert scale: not at all susceptible to very susceptible		
	Perceived risk	2 (0.81)	All: Visual analog scale 0–100% <i>Sum across items</i>	–	Risk Perception Attitude
Mirzaei-Alavije (2019)	- Lifetime risk - Risk in next year	1 1			
	Perceived risk	4 (0.74)	5-point Likert scale: SD to SA <i>Mean of items</i>	Stuifbergen (2000); ¹⁵⁹ Berg (2011); ¹⁶⁰ Tamirat (2014); ¹⁶¹ Tan (2004); ¹⁶² Pinto (2006); ¹⁶³ Patino (2005); ¹⁶⁴ Ayele (2012); ¹⁶⁵ Chao (2005); ¹⁶⁶ Rickheim (2002) ¹⁶⁷	–
Pelullo (2019)	Perceived risk	32	All: 4-point Likert scales: SD to SA	RPS-DD ²⁶	–
	- Optimistic bias	2	<i>Composite of means of each subscale</i>		
	- Personal control - Worry - Comparative disease risk - Comparative envi- ronmental risk	4 2 15 9			
	Perceived risk	12 (0.68)	All: 4-point Likert scales: don't know, decreases risk, increases risk <i>Sum of all items</i>	PRF-T2DM ¹⁹	Familial Risk Perception Personalization Model
Multiple items, no composite score Adriaanse (2003)	Perceived risk	2	11-point scale 0–100%; 6-point scale: negligible to very high	Symptom Risk Questionnaire ¹⁴³	–
	- Risk	1	4-point scale: not a serious disease to a very serious disease		
Johnson (2006)	- Seriousness Perceived risk	1	5-point Likert scale: n/a	Narayan (2003) ¹⁶⁸	–
	- Lifetime risk	1	5-point Likert scale: much higher to much lower		
Adriaanse (2008)	- 3-year risk Perceived risk	2	11-point scale 0–100%; 6-point scale: negligible to very high	Symptom Risk Questionnaire ¹⁴³	–

Table 4 (continued)

Author (year)	Construct ^a Subconstruct	# items (α)	Response options ^b Scoring	Source(s) for scale/item(s)	Guiding theory, model, or framework
	- Risk	1	4-point scale: not a serious disease to a very serious disease		
Harle (2008)	- Seriousness Perceived risk	1	Probability scale 0–100 in 5-point increments: n/a	Walker (2003) ²⁶	–
	- Absolute	1	7-point Likert scale: n/a		
Paddison (2009)	- Relative Perceived risk	1	Scale 0–100%: with 10-point intervals	Weinstein (2009) ¹⁶⁹	–
	- Personal	1	5-point scale: much lower to much higher		
	- Comparative	1			
Dickerson (2012)	Perceived risk	1	5-point ordinal scale: no chance to certain to occur	–	–
	- 10-year risk	1			
	- Lifetime risk	1	5-point ordinal scale: no chance to certain to occur		
Heideman (2012)	Perceived risk			Revised Illness Per- ception Question- naire; ¹⁷⁰ Claassen (2010) ¹⁷¹	Health Action Process Approach
	- Causal beliefs	5	5-point Likert scale: definitely not to definitely		
	- Comparative risk	1	7-point Likert scale: a low lower to a lot higher		
-	- Risk estimation	1	7-point Likert scale: very small to very big		
Godino (2014)	Perceived Risk			Diefenbach (1993), ¹⁴⁶ Lipkus (2000) ¹⁷²	–
	- Absolute	4			
	- Comparative	2			
	Scale 0–100: certain to happen to certain not to happen; 5-point Likert scale: very likely to very unlikely	–			
5-point Likert scale: much less likely to much more likely					
Winter (2014)	Perceived risk			Hurd (2009); ¹⁷³ Man- ski (2004) ¹⁷⁴	–
	- 5-year risk	1	Scale 0–100: n/a		
	- Lifetime risk	1	Scale 0–100: n/a		
Amuta (2015)	Perceived risk	3 (0.85)		–	–
	- Comparative risk	1	5-point Likert scale: much lower to much higher		
	- 5-year	1	Scale 0–100: no chance to definitely will get		
	- Lifetime	1	Scale 0–100: no chance to definitely will get		
Vlaar (2015)	Perceived risk			Claassen (2012) ¹⁷⁵	Common Sense Model
	- Causal beliefs	12	3-point scale: n/a		
	- Susceptibility	3 (0.63)	5-point Likert scale: n/a		
	- Controllability		5-point Likert scale: n/a		

Table 4 (continued)

Author (year)	Construct ^a Subconstruct	# items (α)	Response options ^b Scoring	Source(s) for scale/item(s)	Guiding theory, model, or framework
Kharono (2017)	Perceived risk		All: 5-point Likert scale: SA to SD	–	–
	- Comparative risk	1			
	- Worry	1			
Kowall (2017)	Perceived risk			–	–
	- Present moment risk	1	6-point Likert scale: negligible to very high		
	- Risk in upcoming years	1	3-point scale: Yes, No, I don't know		
Wu (2017)	Perceived risk			Leventhal (1992); ¹⁷⁶ Marteau (2006) ¹⁷⁷	Common Sense Model
	- Lifetime risk	1	5-point Likert scale: never will get to definitely will get diabetes		
	- Seriousness	1	5-point Likert scale: SD to SA		
Paige (2018)	Perceived risk			Witte (1994) ¹⁷⁸	–
	- Comparative risk	1	4-point Guttman scale: almost no chance to high chance		
Orom (2018)	Perceived risk			HINTS	–
	- Personal risk	1	5-point Likert scale: SD to SA		
	- Absolute risk	1	All: 4-point Likert: not at all likely to very likely		
Shaak (2018)	Perceived risk			RPS-DD ²⁶	–
	- Optimistic bias	2	4-point Likert scales: SA to SD		
	- Personal control	4	4-point Likert scales: SA to SD		
	- Worry	2	4-point Likert scales: SA to SD		
Riley (2019)	Perceived risk				
	- Absolute risk	1	3-point ordinal: Increases risk, has no effect on risk, decreases risk		
-	- Comparative risk	1	4-point Likert scale: not at all likely to very likely, I don't know	HINTS	–
-	- Comparative risk	1	3-point Likert scale: less likely to more likely, I don't know		

^aWe used authors' labels for constructs and subconstructs

^bSA strongly agree, SD strongly disagree

Multiple Items, Composite Score. Twelve studies measured perceived risk as a composite score of a single scale.^{29,35–37,46,53,54,63,72,77,80,85} The number of items in the scales ranged from two items^{36,46,54,63} to thirty-two items.⁷⁷ Nine studies used Likert scales,^{29,35–37,54,72,77,80,85} two used visual analog scales,^{46,63} and one used Likert

and ordinal scales.⁵³ Seven studies provided reliability estimates^{37,53,54,63,72,80,85} which ranged from $\alpha=0.68$ ⁷² to $\alpha=0.95$.⁵⁴ One study used two items both combined and separately in analyses to look at overall perceived risk (both items combined), perceived lifetime risk (1 item), and perceived risk in one year (1 item).⁶³

Two studies referenced the RPS-DD as a source,^{77,85} and one study used the PRF-T2DM.⁷² The remaining nine studies did not report using psychometrically evaluated scales.^{29,36,37,46,53,54,63,80,85} Four studies cited a guiding theory, model, or framework including the Theory of Planned Behavior,²⁹ the Health Belief Model,³⁷ Risk Perception Attitude,⁶³ and the Familial Risk Perception Personalization Model.⁷²

Multiple Items, No Composite Score. Eighteen studies used the umbrella term “perceived risk” for scales that included multiple subscales/items, but authors did not calculate a composite score.^{23,28,30,38,45,47,48,60–62,65,66,78,83,84,89,92,94} The most common items or subscales included absolute or lifetime risk ($n=9$),^{29,35–37,46,53,54,63,72,77,80,85} comparative risk ($n=8$),^{45,48,60,62,65,78,84,89} and perceived risk over a specific number of years ($n=5$).^{28,38,47,48,61} Most items or subscales used Likert scales ($n=13$)^{28,45,48,60,61,65,66,78,83,84,89,92,94} or a 0 to 100 response option ($n=7$).^{23,30,45,47,48,83,84} One study referenced use of a psychometrically evaluated scale, the RPS-DD,⁶⁶ and three studies cited guiding models including the Health Action Process Approach⁸⁹ and the Common-Sense Model.^{92,94}

DISCUSSION

This review identified 86 studies assessing perceived risk of developing type 2 diabetes. Six studies aimed to assess the psychometric properties of perceived risk measurement scales, and 80 studies measured individual perceived risk of developing diabetes as part of broader research questions. As with other diseases, this review documents the multiple ways to operationalize perceived risk (e.g., absolute, comparative, worry, seriousness) with no patterns between operationalization and study design, setting, or guiding theory, method, or framework. This lack of consensus in measurement of perceived risk for developing diabetes among those without diabetes parallels the field examining perceived risk of developing diabetes complications among those diagnosed with diabetes,¹² and it parallels findings in other domains such as perceived risk of developing cancer and tobacco control.¹⁰³

Guiding Theories, Models, and Frameworks

While studies have acknowledged the importance of health behavior theories, models, and frameworks for diabetes management,¹⁰⁴ less attention is given in diabetes prevention research to the role of theory.¹⁰⁵ Although perceived risk is an important component of theories such as the Health Belief Model, Protection Motivation Theory, and Theory of Reasoned Action,^{5–7} only 28 out of 86 studies (33%) described a theory, model, or framework as guiding item selection, scale selection, or study design.

Studies incorporating theoretically driven measurement of perceived risk can advance the field in two interconnected ways: (1) to test and describe theoretically hypothesized relationships; and (2) to improve engagement with, enrollment in, and impact of diabetes prevention interventions. Longitudinal studies testing theoretically hypothesized relationships between variables and changes in variables over time can strengthen existing interventions, identify important adaptations needed, and inform future intervention development. For existing evidence-based approaches to diabetes prevention, such as the DPP, participant enrollment and engagement remains suboptimal.¹⁰⁶ Given the linkage between perceived risk and engagement in screening and preventive behaviors, additional research on theory-based measurement of perceived risk is needed to increase these behaviors and engagement in interventions.

Implications of inconsistent operationalization

There was little consistency in how studies operationalized perceived risk, even among those studies referencing the same theory, model, or framework. Some defined perceived risk as a composite of subconstructs such as optimistic bias, worry, and personal control. Others considered these as potential modifiers or covariates. While this lack of consistency is not unique to the study of perceived risk of developing diabetes,^{107,108} it does complicate understanding if and how perceived risk is associated with other constructs and diabetes prevention behaviors. Inconsistent operationalization also limits comparisons across studies. For example, perceived lifetime risk, absolute risk, or comparative risk each measure a particular aspect of perceived risk, and the terms are not interchangeable limiting comparison.^{4,8}

Few studies used the validated measures identified in the six psychometric studies. The RPS-DD²⁶ was the most commonly cited scale. However, use of the instrument varied. For example, some investigators used the single comparative disease risk item to measure perceived risk of developing diabetes,^{31,32,50,51,56,73} while others used a composite score from all RPS-DD subconstructs.^{77,85} This varied measurement, even with one instrument, makes comparisons across studies challenging. For example, a study assessing perceived risk using a composite score of optimistic bias, worry, and personal control may measure a more global, comprehensive latent factor than another measuring perceived risk with only a single item. Finally, using truncated measures may limit our ability to detect patterns of association and whether interventions successfully changed perceived risk.

Study Design and Ability to Identify Changes in Perceived Risk

Finally, the majority of studies ($n=62$) used cross-sectional study designs which provide a snapshot in time of participants' perceived risk and the construct's association with diabetes risk

factors. For example, Joiner et al. used a cross-sectional, single-item perceived risk measure and found that non-Hispanic Blacks and Hispanics with undiagnosed prediabetes were more likely to report no perceived risk for diabetes.⁵⁵ However, such studies are not designed to examine changes in perceived risk over time or factors associated with changes in perceived risk that may lead to improved health outcomes.

The value of perceived risk as a behavioral predictor and potential intervention target is in its prospective, longitudinal effect on preventive behaviors,¹¹¹⁻¹¹³ and the relation between perceived risk and behavior can differ depending on whether it is assessed cross-sectionally or prospectively.^{4,114} At this time, we do not have enough evidence to support that (1) perceived risk of developing diabetes changes over time for those without a diagnosis; (2) it naturalistically changes with adoption of diabetes preventive behaviors; and (3) that interventions can successfully influence perceived risk and thereby motivate performance of behaviors that prevent development of diabetes. These are important areas that warrant additional research.

Pragmatic Measurement

This review captures how perceived risk is measured in multiple settings such as community, hospital, outpatient, and university settings. While it may be ideal to measure a latent construct such as perceived risk using multi-item validated scales, pragmatically this is not always feasible.³ Context is important when deciding how to measure perceived risk, and clinical settings may be most appropriate for one-item measurement while research or intervention studies may allow for more in-depth assessment, for example.

Consideration of context, the target population, and how perceived risk data are utilized can inform the selection of measures and enhance the usability of measures in community, clinical, and intervention research contexts.^{109, 110} An individual's perceived risk of developing diabetes may be influenced by several intersecting factors including individual beliefs and behaviors (e.g., nutrition), biological variables (e.g., family history), and environmental context (e.g., access to healthcare and nutritious foods). Table 4 presents

Table 5 Example Questions and Considerations When Selecting Measures of Perceived Risk Across Clinical Management and Research Intervention Contexts

COMMUNITY/CLINIC CONTEXT:

Who will assess perceived risk and how?

- Measuring perceived risk during clinical encounter with one to two brief items may be necessary due to limited time with provider
- When measuring perceived risk when implementing a community-based diabetes prevention program, limited interactions and type of interactions with participants may dictate type of measures used
- Measuring perceived risk with subscales and multiple items may require additional resources (e.g., front staff, patient portal, patient reminders) to ensure patient answers questions before clinical encounter

What is the patient population?

- Patient health literacy and numeracy may limit measurement or number of items used
- Peers and environment may influence who patient compares him/herself to if asked comparative risk

How will the data be used?

- If used to guide provider-patient discussions, one to two brief items may be sufficient
- If used to identify patients eligible for diabetes prevention or disease management programs, measurement of multiple subconstructs or modifiers can provide more nuanced details
- How community organizations share data with other entities (e.g., healthcare systems) may impact type of data collected

Is actual/calculated risk known?

- Combined with perceived risk, provider knowledge of patient's actual risk can guide provider-patient discussions about behaviors
- Patient knowledge of actual risk can influence perceived risk. Provider should know whether patient knows his/her actual risk to better interpret perceived risk

Are related constructs measured?

- Measuring perceived severity, for example, in addition to perceived risk can highlight patient knowledge gaps and areas where additional patient education about disease may be needed

RESEARCH INTERVENTION CONTEXT:

What is the theoretical framework?

- Selecting and measuring variables grounded in theory can describe hypothesized relationships a priori
- A validated or reliable instrument may have the same theoretical underpinnings as the theoretical framework associated with the intervention potentially eliminating the need to create a new measure

What is the participant population?

- Participant health literacy and numeracy may limit measurement or number of items used
- Intervention context may mean additional resources are available to administer survey which can help reduce limitations of participant health literacy or numeracy (e.g., research assistant to administer via structured interview)
- Peers and environment may influence who participant compares him/herself to if asked comparative risk

How will the data be used?

- If using to identify patients eligible for a specific intervention or program, measurement of multiple subconstructs or modifiers can provide more nuanced details
- If comparing to broader literature, selecting validated instrument may facilitate comparison across studies using the same instrument
- If perceived risk is not part of primary research question, limiting items related to the construct can reduce participant survey burden

Are related constructs measured?

- Measures incorporating multiple subscales or constructs may help identify specific mechanisms through which the intervention works
-

a series of example questions and considerations that diabetes researchers and clinicians can ask to guide selection of the most appropriate perceived risk measure given context, population, and how data will be used. Answers to the questions may have different implications for each.

As noted in Table 5, these aspects of perceived risk, such as perceived lifetime or comparative risk, may differ by contexts depending on a patient's age or comparator peer group. A clinician's or researcher's goals can help guide the selection of which aspect of perceived risk to measure. For example, if one aims to predict behavior change, comparative risk assessments may be most appropriate as comparative risk is strongly associated with behavioral intentions.¹¹

Strengths and Limitations

This review synthesizes measures of perceived risk of diabetes among those without the disease. Past reviews have focused on perceived risks for diabetes-related complications¹² and diabetes risk models and scores.^{12,13} This review is the first to categorize how the perceived risk construct is measured in the diabetes prevention domain (i.e., single item, multiple items with composite score, multiple items no composite score). It adds to the literature assessing measurement of perceived risk of other diseases and health behaviors, such as cancer and cancer screening,¹¹⁵ tobacco control,¹⁰³ and vaccination,^{112,116} areas with robust literature examining perceived risk and behavioral outcomes. Yet, similar inconsistencies in measurement of perceived risk can be found in these areas of research with no consensus among investigators on how best to measure the construct.^{103,108} Finally, this review is the first to examine the use of theory, models, and frameworks in studies measuring perceived risk of developing diabetes, and it points to the need for more reliance on theory in measurement.

This review also has limitations. The review did not include a search of gray literature and non-English studies. In addition, reviewers did not contact study authors when excluding articles that included mixed populations with no ability to separate results (e.g., mixed < 18-year and ≥ 18-year-old populations, participants with and without known type 2 diabetes). This may have missed studies that could have been included if study authors were able to provide data according to inclusion criteria. Finally, after piloting the search criteria between two reviewers, only one reviewer completed screening and full text reviews. While a second reviewer validated the extracted data, double screening and data extraction increases transparency and reproducibility.¹¹⁷

CONCLUSION

Aspects of perceived risk of developing diabetes are routinely assessed and discussed with patients during clinical encounters focused on health promotion, diabetes screening, and diabetes prevention. Single-item assessment of

perceived risk may be suitable for focused discussions in clinical practice. However, structured assessment of perceived risk of developing diabetes measured in a consistent, standardized format is important for clinical researchers and preventive program managers to understand (1) if changing perceived risk influences adoption of behaviors to prevent development of type 2 diabetes and (2) if perceived risk changes over time with education and intervention. This review characterizes the diverse approaches to assessing perceived risk of developing diabetes and provides questions to consider when selecting measures of perceived risk across clinical and intervention contexts. Similar to Kaufman and colleagues' review of perceived risk measurement in tobacco control research¹⁰³, this review illustrates the need to harmonize measurement of perceived risk across the field of diabetes prevention to enable comparison across studies and across chronic disease domains.

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