Assessing cardiovascular disease risk factors in underserved young adult populations

by

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B.S., University of Ghana - Ghana, 2005
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AN ABSTRACT OF A DISSERTATION

submitted in partial fulfillment of the requirements for the degree

DOCTOR OF PHILOSOPHY

Department of Food, Nutrition, Dietetics, and Health
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Abstract

Cardiovascular disease (CVD, i.e., disease of the heart and blood vessels) is a major cause of death in the United States and globally. Despite the importance of CVD risk assessment for effective CVD prevention intervention, current assessment tools use either clinical or non-clinical factors alone or in combination to assess disease risk(s). However, in limited-resource or underserved communities, where members have less or no health insurance coverage; higher cost barriers to health care access; and poor self-rated general health, disease diagnoses with such clinical tools may be elusive. Additionally, understanding people's motivation to participate in health-promoting behaviors is essential for the maintenance and improvement of health.

The primary aim of this study was to develop a non-clinical-based survey instrument to be used to identify or assess CVD risks in underserved young adult populations. The study's specific objectives were to: (1) conduct a systematic literature review to critically appraise and summarize existing CVD risk assessment tools; and (2) adapt or develop a new instrument, incorporating a behavioral component into it, and pilot-test it among young adults from underserved populations.

Two online electronic databases – PubMed and Scopus – were searched to identify existing risk assessment tools available in English only and published between 2008 and 2019. A total of 21 distinct CVD risk assessment tools were identified; six of these did not require clinical or laboratory data in their estimation (i.e., were non-clinical). Development of the new instrument, *Need-2-Know* CVD risk assessment questionnaire, occurred in three phases: focus group discussion (FGD); instrument development, and test-retest reliability testing of questionnaire.

The final *Need-2-Know* CVD risk assessment questionnaire comprised a total of 59 items assessing behavioral risk factors (tobacco use, alcohol consumption, diet, and physical activity), basic psychological needs satisfaction, personal medical history, type of health insurance, and demographic data. Test-retest correlation coefficients ranged from 0.037 to 0.736 for items in the Tobacco use subscale; 0.471 to 1.000 for the Alcohol use items; 0.337 to 0.664 for Diet items; 0.098 to 0.726 for PA items; and 0.601 to 0.724 for the psychological needs satisfaction. Even though most of the correlation coefficients for Diet and PA subscales were significant, they showed unacceptable to poor reliability.

To the best of our knowledge, the systematic review conducted as part of this study is the first to identify tools or instruments that have been used to assess CVD risk factors in the young adult population. The items on the subscales of the *Need-2-Know* CVD risk questionnaire showed acceptable consistency across items. However, the questionnaire showed unacceptable to poor reliability. That notwithstanding, the *Need-2-Kow* CVD risk assessment questionnaire can be a valuable tool for assessing CVD risks among young adults in a non-clinical and public health settings.

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Dedication

I dedicate this dissertation to the memory of my late elder sister, ***Daphne Naa Darkua Bampoe,*** who died from a cardiac arrest on Thursday, September 17, 2020. *Daph*, I am sure you would have been proud to see the product of my research. Rest peacefully, Sis! May this research help save more lives from cardiovascular diseases!

To my children- *Sean, Simone, and Samuel*, you always inspire me to be a better person in many ways than one, and I bless God for placing you all in our lives.

Chapter 1 - Introduction

In 2017–2018, 42.4% of American adults were obese; 40% of young adults aged 20–39y were obese.[1] Obesity is a risk factor for cardiovascular disease (CVD), diabetes, and related health conditions such as coronary heart disease (CHD), heart failure and stroke.[2] CVD is a term used to classify diseases of the circulatory system, i.e., the heart and blood vessels[3] and includes CHD, cerebrovascular diseases (e.g. deep vein thrombosis, stroke, transient ischemic attack and aneurysms), rheumatic heart diseases and Chagas disease.[4] CHD is the narrowing of the inner walls of the blood vessels that transport blood to the heart (arteries) due to a build-up of a waxy substance (plaque)[3] and is the number one cause (45.1%) of CVD-related death in the United States, with stroke (16.5%) and high blood pressure (9.1%) being the next two highest.[5] CVD is the leading cause of death globally and in the United States; it is estimated that one in every three deaths is attributable to CVD.[5,6] Globally, it is projected that by 2030, about 23.6 million deaths will result annually from CVD events.[5]

Lack of health insurance, especially among vulnerable and underserved populations, hinders early diagnoses of chronic diseases.[7] An underserved population is defined as "one of ethnic and/or racial minority status and of low socio-economic status (SES)".[8] A vulnerable population may be classified as members of minority populations or individuals who have experienced health disparities (i.e., existing differences in health among individuals or populations). Examples of vulnerable populations include Latino populations; African American populations; American Indians/Alaskan Native (AI/AN) populations; refugees; individuals with limited English Proficiency (LEP); young adults and post-secondary graduating students who do not have coverage options through a parent's plan, a student plan, or an employer plan; new mothers and women with children; individuals with disabilities; Medicaid-eligible consumers

who are not enrolled in coverage despite being eligible for Medicaid; and religious minorities.[9] Generally, there are racial/ethnic differences in self-perceived health status, prevalence of health-related risk factors and chronic conditions, and health-care access.[2,10]

Cardiovascular risk assessment is necessary for effective CVD prevention intervention, especially in high-risk individuals and underserved populations.[11] Early screening in youth is encouraged to prevent cardiovascular events in adulthood because current evidence suggests that CVD risk factors are present in adolescence.[11] To date, both paper-based and electronic risk scores have been clinically applied to estimate absolute risks using patients' data and published equations.

Current risk assessment tools either use family medical history alone or in combination with clinical (e.g., cholesterol level, blood pressure, and glucose level) or non-clinical factors (e.g., gender, race, weight, height, dietary and physical activity) to assess disease risk. However, these tools have some limitations, such as non-representative or historically dated populations, limited ethnic representation, narrowly defined and unreliable endpoints.[12] Further, in resource-deficient or minority communities, where members have less or no health insurance coverage, higher cost barriers to health care access, and poor self-rated general health, disease diagnoses with a family health history tool may be elusive. Thus, until an illness becomes life-threatening, it may be difficult to detect it and even attempt to control it.[7,13] For such a population, a non-clinical-based tool may be useful for disease risk assessment. Lastly, some people may be ignorant of their family history of diseases, so relying only on family history information may be problematic.

Understanding people's motivation to participate in health-promoting behaviors is essential for the maintenance and improvement of health.[14] Human motivation is defined as "the

internal condition that activates behavior, energizes it, and gives it direction (p.79)."[15] Motivation can be extrinsic (stemming from expectations external to the individual), intrinsic (internal to an individual), or beliefs about oneself, others, and behavior outcomes. Social psychological theories of human motivation are commonly applied in health promotion.[15] One of such theories is the self-determination theory (SDT), which provides a conceptual framework for understanding motivational processes and planning health promotion interventions.[14] SDT recommends that people's social contexts and environmental developments be explored to determine how their autonomy, competence, and relatedness are being affected.[16] Such information is useful in the context of CVD risk assessment because it may provide an understanding of why people fail to be screened.

Goals and Objectives

The primary aim of this study is to develop a non-clinical-based survey instrument to be used to identify or assess CVD risks in underserved young adult populations. The secondary aim is to examine the underlying factors influencing people's motivation (willingness) to be screened for CVD risks.

The specific objectives are:

1. To conduct a systematic review and identify existing tools for CVD risk assessment and possible gaps.
2. To adapt or create a new instrument, incorporating a behavioral component into it, and pilot-test it among young adults from underserved populations.

Public Health Significance

High-quality systematic reviews can offer a broad overview of the measurement of Patient-Reported Outcome Measures (PROMs, i.e., health outcomes measured and directly reported by the patient) and evidence-based recommendations for selection of the appropriate PROM for a given purpose.[17] For this reason, this study will use a systematic review to select the appropriate instrument to be used to achieve the purpose of the study. To the best of our knowledge, this is the first study to design an instrument specifically to be used in a non-clinical or non-medical setting. Such an instrument is useful because it will improve CVD screening rates, help recognize symptoms and understand the different CVD risk profiles in underserved populations. The proposed instrument may further improve chronic disease detection among racial minority and low-income populations and potentially, reduce existing health disparities. Finally, the results from this study will add to the growing literature on the application of SDT in health promotion, particularly cardiovascular health among young adults.

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Chapter 2 - Literature Review

Overview of Cardiovascular Disease (CVD) Burden

Approximately 2,200 Americans die of CVD daily (i.e., one death every 40 seconds).[1] Risk factors for CVD include elevated blood cholesterol, high blood pressure (hypertension), family history of heart disease, overweight/obesity, physical inactivity, high-fat and sodium diets, and tobacco smoking.[2,3]

Health Disparities and CVD

Health disparities are differences in health outcomes among populations. Health disparity can be defined as "a particular type of health difference between individuals or groups that is unfair because it is caused by a social or economic disadvantage"[4] and achieving health equity and elimination of health disparities is one of the four overarching goals of *Healthy People 2020.*[4] Social determinants of health (SDH) also account for disparities in health. The World Health Organization defines SDH as "the conditions in which people are born, grow, live, work and age."[5] SDH could be social or physical and include factors such as availability of adequate resources, access to educational and employment opportunities, health care access, transportation options, social support, social norms and attitudes (e.g., discrimination, racism, and government mistrust), social disorder, residential segregation, literacy and culture. *Healthy People 2020* sub-classifies SDH into five distinct groups, namely economic stability; education; health, and health care; neighborhood and built environment; and social and community context.[6]

Factors contributing to health disparities in the United States (U.S.) include ethnicity, race, geography, SES, individual behaviors (e.g., diet and exercise), genetics, insensitivity to the needs and differences of patients from diverse backgrounds, access to medical care, insurance coverage, cultural competency and available infrastructure or health care facilities.[7] Race refers

to “a person’s self-identification with one or more social groups – White, Black or African American, Asian, American Indian and Alaska Native, Native Hawaiian and Other Pacific Islander, or some other race”.[8] Ethnicity, as used in this study, refers to whether a person is either Hispanic or non-Hispanic.[8]

Specifically, racial health disparities may arise from patient-level factors (i.e., clinical appropriateness, treatment refusal, or patient preferences); health care system attributes and delivery of health care (i.e., language barriers, geographic location of health care facilities, or changes in health care funding); biases and stereotypes of health care providers; and SES (i.e. income and education).[9]

Compared to whites, racial minority populations have poor nutrition profiles and dietary behaviors due to diet-related disparities. Diet-related disparities refer to “differences in dietary intake, dietary behaviors, and dietary patterns in different segments of the population, resulting in poorer dietary quality and inferior health outcomes for certain groups and an unequal burden in terms of disease incidence, morbidity, mortality, survival, and quality of life.”[10]

CVD Risk Factors

Chronic or degenerative (i.e., non-infectious) diseases are influenced by a group of symptoms or factors known as risk factors. These risk factors often affect each other and may be environmental, behavioral, social or genetic.[11] The two main behavioral factors that cause obesity and most degenerative diseases are food intake and physical activity.[12] For example, consuming a high-fat, sodium and added sugar diet increases risk for obesity and obesity-related conditions. Current obesogenic (i.e., obesity-promoting) and mechanized environments contribute to the intake of high caloric-diets and inadequate physical activity.[12]

There are racial differences in the prevalence, morbidity and mortality from CVD and its associated major risk factors, with African Americans, Hispanics/Mexican Americans, persons with low SES, residents of southeastern U.S. and the Appalachians being the most affected.[13,14] For instance, irrespective of gender or educational status, African Americans have high rates of hypertension.[13] Significant disparities exist in tobacco use in the U.S. by race, ethnicity, educational level, SES, geographic region, sexual minorities, and severe mental illness.[15] For example, the prevalence of tobacco use is greater among American Indian/Alaska Natives and lesbian, gay, bisexual, and transgender populations.[16]

Smoking and Heart Health

Smoking is the major cause of preventable disease, disability, and death in the U.S. As of 2019, approximately 51 million American adults used any tobacco product, with cigarettes being the popular product used by adults (34.1 million).[17] Reasons why youth and young adults smoke include curiosity, flavoring/taste, and low perceived harm than other tobacco products.[18]

Smoking is associated with adverse health outcomes, and it damages almost every organ in the body.[15] Cigarette smoking and involuntary exposure to secondhand tobacco smoke [i.e., the smoke from the burning end of the cigarette together with what is breathed out by smokers] cause coronary heart disease (CHD), stroke, aortic aneurysm [i.e., the protrusion of blood vessels that can burst, resulting in death], and peripheral artery disease (PAD).[19,20] Additionally, smoking adversely impacts the body by causing inflammation and impaired immune function.[15]

Smoking-related cardiovascular risks increase with the quantity of cigarettes smoked and the duration of smoking, with a marked increase in risks from exposure to secondhand smoke or smoking few cigarettes.[19] For instance, evidence suggests that exposure to secondhand smoke

increases stroke risk by 20–30%. Compared to non-smokers, active smokers have 30–40% increased risk of developing diabetes.[15]

Tobacco smoke comprises several chemical substances such as oxidizing chemicals, nicotine, carbon monoxide (CO), and particulate matter, and these increase the risk of CVD. However, the three commonest constituents of cigarette smoke are nicotine, CO, and oxidant gases.[19] Nicotine is a toxic and addictive chemical substance naturally occurring in tobacco. It is easily absorbed and transported through the body. It impacts several biological processes related to fetal growth and development, immune function, the cardiovascular system, the central nervous system, and carcinogenesis.[15] Nicotine increases heart rate, cardiac contractions, blood pressure, and the narrowing of coronary arteries. CO inhibits the transport of oxygen to the heart and other tissues by aggressively binding with hemoglobin to form carboxyhemoglobin.[19] Oxidizing chemicals (e.g., oxides of nitrogen and free radicals) increase lipid peroxidation and potentially cause inflammation, impaired functioning of the lining of blood vessels, oxidation of low-density lipoprotein, and platelet activation.[15] Being exposed to the particulate matter in smoke results in oxidation stress and cardiovascular autonomic disturbances that can lead to acute coronary events (ACEs, e.g., myocardial infarction and sudden death).[15]

Smoking cessation is recommended for preventing the adverse health outcomes associated with smoking.[15] Electronic cigarettes (also known as *e-cigs, e-hookahs, mods, vape pens, vapes, tank systems, and electronic nicotine delivery systems* [ENDS]) are used by some adults as a substitute for conventional cigarettes. The prevalence of e-cigarette use is higher among adults aged 18–24 (24.5%) and 25–44 years (49.3%).[17] E-cigarettes are battery-powered devices that produce an aerosol to be inhaled by heating a liquid containing nicotine, flavorings, and other additives.[17] Though the research evidence on the health effects of e-cigarettes is still

emerging, it has been shown that e-cigarettes contain relatively fewer toxic constituents than the conventional cigarette smoke. Nevertheless, the toxic constituents of e-cigarette include nicotine, carbonyl compounds, and volatile organic compounds that potentially result in deleterious health effects.[18]

Alcohol and Heart Health

Alcohol is a psychoactive substance (i.e., having the ability to impact the function of the central nervous system) and the harmful use of alcohol is a major global risk factor for diseases.[21] A combination of two psychoactive substances (e.g., alcohol and tobacco) could either amplify, diminish or counteract the effect of the first substance.[21] Factors influencing alcohol consumption include gender, age, health status, economic status, lifestyle habits, religious and cultural norms.[21]

In 2016, approximately one in every five alcohol-attributable deaths were associated with CVD. The three frequently consumed alcoholic beverage were spirits (44.8%), beer (34.3%), and wine (11.7%).[21]

Moderate alcohol consumption refers to up to 1 and 2 drinks daily for women and men, respectively.[22] On the contrary, excessive drinking is the consumption of at least four drinks per day or at least eight drinks per week for women and a minimum of 5 drinks per day or 15 drinks per week for men.[22]

The harmful effects of alcohol consumption can be expressed via three broad mechanisms, namely toxic effects of alcohol, dependence potential, and intoxication.[21] It is very common for heavy alcohol drinkers to also be heavy tobacco smokers.[21]

Healthy Eating and Heart Health

According to the *2020–2025 Dietary Guidelines*, a healthy eating pattern (i.e., an individual's overall intake of food and beverages over time) comprises a variety of vegetables from all the five vegetable subgroups (i.e., dark green; red and orange; beans, peas, and lentils; starchy; and other), fruits (especially whole fruit), grains (with about half being whole grain), fat-free and low-fat (1%) dairy, a variety of protein foods, and oils, limiting foods and beverages higher in added sugars, saturated fat, and sodium/salt, and alcoholic beverages.[23]

A healthy eating pattern promotes healthy body weight and reduces the risk of CVD. For instance, vegetables and fruits are associated with reduced risks of many chronic diseases. The consumption of whole grains is also linked with low body weight. Substituting saturated fats with unsaturated fats is associated with reduced levels of total cholesterol and low-density lipoprotein cholesterol (LDL-cholesterol) in the blood, resulting in reduced risks of CVD events and CVD-related deaths.[22] Increased consumption of trans fat increases CVD risk partly by increasing the level of LDL-cholesterol.[22] The amount of sodium an individual consumes is directly proportional to his/her food and beverage intake. In adults, high intake of sodium increases blood pressure, a common CVD risk factor. Thus, reduction in sodium intake can lower blood pressure, especially among people with prehypertension and hypertension.[22]

Physical Activity and Heart Health

Due to poor quality eating patterns and physical inactivity, approximately 117 million Americans suffer from chronic diseases, including CVD, high blood pressure, type 2 diabetes, certain cancers and poor bone health.[22] To promote good health and reduce chronic disease risks, Americans are encouraged to maintain a healthy body weight through a balance of food intake and physical activity (PA).[22] The *Physical Activity Guidelines for Americans* encourages adults

to engage in a minimum of 150 minutes (2 hours and 30 minutes) of moderate-intensity aerobic PA or 75 minutes a week of vigorous-intensity aerobic PA, as well as muscle-strengthening exercises on 2 or more days per week. This same recommendation is applicable to adults with chronic health conditions and disabilities. Aerobic activity is any activity that makes your heart beat faster, whereas a muscle-strengthening activity is an activity that makes your muscles work harder than they usually would.[24]

Engaging in at least 150 minutes of moderate-intensity PA per week results in substantial reductions in CVD risk.[16] Though both aerobic and muscle-strengthening PA are encouraged to improve blood pressure, approximately 80% of adults do not meet the recommended guidelines for aerobic and muscle-strengthening activity.[24]

Regular PA promotes the maintenance of a healthy body weight, prevention of excess weight gain, reduces risks of CVD mortality, CVD (including heart disease and stroke), hypertension, adverse blood lipid profile, type 2 diabetes, and metabolic syndrome.[16,22] Light-intensity PA prevents CVD.[16]

Determining CVD Risks

An individual's health is strongly dependent on his or her socio-economic position or status (i.e., education, income, occupation, level of assists, etc.).[25] Further, one's SES may determine the community he desires to or lives in.[25]

Two major causes of death in the U.S. are heart disease and stroke.[16] Risk factors such as smoking, hypertension, type 2 diabetes, high levels of LDL-cholesterol, and low cardiorespiratory (i.e., relating to the heart, lungs, and blood vessels) fitness increase CVD risk.[16]

Toward its goal to improve the cardiovascular health of Americans by 20% by reducing CVD and stroke-related death by 20%, the American Heart Association (AHA) developed the *ideal*

cardiovascular health (ICH) concept. ICH is defined as "the presence of both ideal health behaviors (non-smoking, body mass index <25 kg/m^2, physical activity at goal levels, and pursuit of a diet consistent with guideline recommendations) and ideal health factors (untreated total cholesterol <200 mg/dL, untreated blood pressure <120/<80 mm Hg, and fasting blood glucose <100 mg/dL)."[26] The AHA's health campaign, *Life's Simple 7* provides seven basic steps to attain ideal cardiovascular health[27]:

1. Manage blood pressure
2. Control cholesterol
3. Reduce blood glucose
4. Get active
5. Eat better
6. Lose weight or keep a healthy weight
7. Stop smoking

Approximately 92% of U.S. adults have at least one of these seven cardiovascular health metric at poor levels.[27] Additionally, social risk factors, such as low family income, low educational level, minority race and single-living status hinders the achievement of better or ideal cardiovascular health.[27] For instance, most racial minority populations (including African Americans) lack health insurance coverage, thus limiting their access to health services and making the early detection or diagnosis of chronic diseases less likely.[7] Thus, population-level strategies for CVD health promotion in these populations are warranted.[1,26]

To reduce disparities in CVD outcomes and ultimately promote cardiovascular health, interventions need to focus on primary and secondary prevention in disadvantaged populations, as well as address root social causes of CVD (i.e., poverty, illiteracy and unemployment).[28]

When tackling CVD risk factors and their related health challenges, having an understanding of how racial or ethnic minorities and underserved communities define health, their health beliefs, health-seeking behaviors, and how their attitudes, behaviors and beliefs influence health outcomes is fundamental.[29] Figure 1 provides the conceptual framework designed by the author to explain the complex relationships among the various CVD risk factors.

To facilitate initiation and sustenance of behavior change, it is important for health intervention models to have a strong education component that includes family and community, as well as emphasizes the link between dietary intake and health status or well-being.[30]

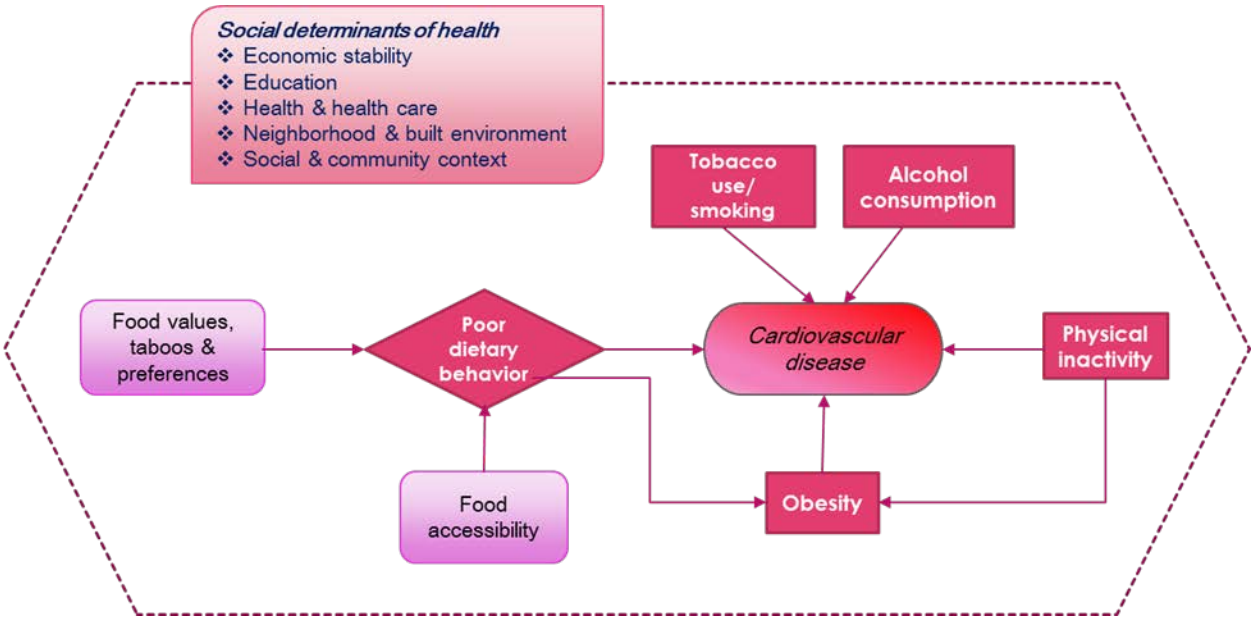

Figure 1. Conceptual Framework for the Interplay of Factors Promoting CVD Risk

[Note: Within the hexagon (dotted line) are the modifiable CVD risk factors, including some factors influencing dietary behavior and these factors are directly impacted by the social determinants of health.]

Current CVD Risk Assessment Tools

Risk assessment is useful in raising population awareness of life-threatening diseases such as CVD; providing risk information to individuals or subgroups; and motivating recommended changes in lifestyle behaviors or therapies.[31] There are two types of risks in CVD risk assessment

– absolute (total/overall) and relative risks. Absolute risk refers to the overall risk of disease occurrence in an individual, whereas relative risk implies the individual's risk in comparison to other individuals with similar characteristics. Total CVD risk predicts the chance of developing CVD over a given time frame based on all major CVD risk factors (age, sex, smoking habit, systolic blood pressure). For example, a 10-year risk estimate expresses the number of cardiovascular events likely to occur within ten years in 100 individuals with similar risk factors.[32]

Generally, CVD risk assessment tools predict an individual's short-term cardiovascular risk by assigning a global risk score based on prediction models or algorithms.[33] CVD risk assessment is often achieved by using prediction models or algorithms through the assignment of scores. Some common risk assessment scores include the Framingham risk score (FRS), the National Cholesterol Education Program Adult Treatment Panel III (NCEP-ATP III)] risk estimator, Framingham global CVD, the Prospective Cardiovascular Munster (PROCAM), QRISK, Reynolds risk score and the European Systematic COronary Risk Evaluation (SCORE) algorithm.[31]

Study Rationale

Risk assessment tools either use family medical history alone or in combination with clinical (e.g., cholesterol level, blood pressure, and glucose level) or non-clinical factors (e.g., gender, race, weight, height, dietary and physical activity) to assess disease risk. Family health history tools are clinically used to assess patients' familial risk levels because they provide information related to genetic, environmental, and behavioral factors in disease etiologies.[34] However, in resource-deficient or vulnerable communities, where members have less or no health insurance coverage; higher cost barriers to health care access; and poor self-rated general

health, disease diagnoses with a family health history or clinically administered tool may be elusive. Thus, until an illness becomes life-threatening, it may be difficult to detect it and even attempt to control it.[35,36] For such a population, a non-family history-based tool may be useful for risk assessment. Furthermore, some people may be ignorant of their family history of diseases, so relying only on family history information may be problematic. Additionally, environmental risk factors cannot be captured with family history tools.

Chronic disease risk is highest during middle age and older adulthood. Thus, intervention in young adults can prevent disease progression and alleviate health care costs.[2,37] Young adult refers to the population between the ages of 18 and 34 years old.[38] Though this population may currently not exhibit any symptom of diseases, they may be engaging in certain health risk behaviors (e.g., smoking, poor dietary habits, and physical inactivity) that may increase their risks to be affected in future. Furthermore, targeting young, African American adults for behavior change interventions could help reduce CVD risks by enabling them to understand how cardiovascular risk factors impact their health; assess their own family health history, health behaviors and lifestyle choices, as well as improve their self-efficacy to engage in health behaviors that will improve their cardiovascular health in the long-term.[2]

Nineteen percent (~ 46.7 million) of Americans age 18 years and over, have some college or no degree (i.e., they enrolled in postsecondary institutions but did not complete and are no longer enrolled), constituting 30.1 million White, 6.6 million Black/African American, 6.7 million Hispanic and 1.9 million Asian.[39] Forty-two percent of 18–24-year old Americans are enrolled in degree-granting postsecondary institutions; 44.5% of this population being White, 36.1% Black/African American, 36% Hispanic, 39% Pacific Islander and 25.7% American Indian/Alaska Native.[39] Further, 90 % (~194 million) of US adults age 25 and older have a

minimum of a high school diploma (Figure 2) and 34% of this population possesses a Bachelor's or an advanced degree.[40]

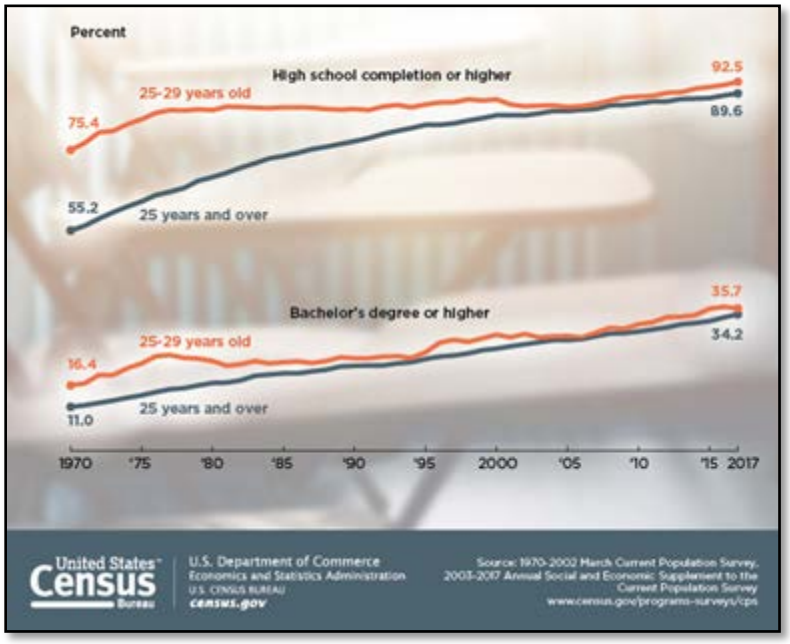

Figure 2. Levels of Education: Percentage of the U.S. Population Completing High School, Bachelor's or Higher

[Source: U.S. Census Bureau[41]**]**

This implies that approximately half of high school graduates (56%) are not enrolled in college. Thus, to provide a broader reach and greater generalizability of expected findings, this study will target young adults either enrolled or not enrolled in college.

The purpose of this study is twofold – first, to develop and validate a composite measure to be used to determine CVD risks in a non-clinical setting; and secondly, to examine the motivational characteristics, particularly those related to dietary, physical activity, smoking and alcohol behaviors, to better understand how they influence people's decision to be screened for CVD risk. This is important because the development of a risk assessment measure may not guarantee that everyone will use it. Thus, understanding the factors that influence people's motivation to be screened for disease risks is key.

Theoretical Framework and Logic Model

Psychological theories that have been used in intervention research to promote long-term health behaviors, such as physical activity and smoking cessation, include Self-Determination Theory (SDT),[42,43] Theory of Planned Behavior (TPB),[44] Social Cognitive Theory (SCT),[45] Transtheoretical Model (TTM)[46,47] and Social Ecological Model (SEM).[48] Most commonly applied behavior theories in health research include SCT, Health Belief Model (HBM), TPB and Transtheoretical Model/ Stages of Change (TTM/SOC).[49] The major constructs of these models and their applications in nutrition education are outlined in Table 1.

Table 1. Commonly Used Health Behavior Change Theories and Their Constructs

Theory/ Model	Constructs/ Concepts
Social cognitive theory	
	Outcome expectations (physical or material) - what individuals expect to get physically from making a behavior change.
	Outcome expectations (social) – social benefits expect to get if they make a behavior change.
	Outcome expectations (self-evaluative) – what individuals expect to feel about themselves if they make a behavior change.
	Expectancies – the values individuals place on these physical, social, and self-evaluative outcomes.
	Barriers or impediments – include the perceptions of personal barriers to acting and actual environmental barriers.
	Self-efficacy – individuals' confidence or beliefs in their personal ability to perform the given behavior.

Theory/ Model	Constructs/ Concepts
	Behavioral capacity/ capability - individuals' food and nutrition-related knowledge and cognitive, affective, and behavioral skills needed to enact the behavior.
	Self-regulation/self-direction skills – the ability to direct or control own actions or behaviors through conscious, intentional choices; involves skills in being able to create appropriate action plans and to follow through with them.
	Observational learning/ modeling – learning to perform a behavior by observing someone modeling the behavior and its consequences.
	Reinforcement – Responses to individuals' behavior that increase or decrease the likelihood of its occurrence.
Social ecological model[50,51]	
	Intrapersonal factors – individual characteristics (i.e., knowledge, beliefs, and self-concept).
	Interpersonal processes and primary groups – an individual's social environment that surround the individual and influence behavior.
	Institutional or organizational factors – workplaces, churches, and other organized social institutions.
	Community factors – relationships among organizations and institutions.
	Public policies – policies related to healthy practices.
Health belief model[50,52]	

Theory/ Model	Constructs/ Concepts
	Perceived susceptibility – belief about the chances of personally experiencing a risk for a particular health-related condition.
	Perceived severity – level to which one feels a health-related condition is severe.
	Perceived threat or risk – a combination of perceived severity and personal susceptibility.
	Perceived benefits – belief in the efficacy of the advised action to reduce the risk or seriousness of the condition.
	Perceived barriers – beliefs about the psychological or tangible costs of acting.
	Self-efficacy – confidence in one's ability to perform the behavior/ action.
	Cues to action – external events that prompt one to act.
Theory of planned behavior[50]	
	Beliefs about behavior/ outcome expectations – individuals' beliefs that the behavior leads to certain desired or negative outcomes (in the areas of health, personal, social, etc.).
	Attitudes (cognitive/instrumental) – individuals' favorable or unfavorable judgments about a given behavior.
	Attitudes (affective/experiential) – individuals' emotional response to the idea of performing the behavior.

Theory/ Model	Constructs/ Concepts
	Subjective (injunctive) norms – individuals' beliefs that people who are important to them either approve or disapprove of the behavior.
	Descriptive norms – individuals' beliefs about important others' attitudes or behaviors about the behavior.
	Perceived behavioral control (self-efficacy/difficulty) – individuals' perceptions about factors that will make it easy or difficult to perform the behavior and whether there are environmental barriers to action.
	Behavioral intentions – individuals' perceived likelihood of taking a given action.
Transtheoretical Model (Stages of change)	
	Precontemplation – stage in which individuals are not aware of, or not interested in, a behavior or that might improve their health. It also includes individuals who might have had failed earlier attempts at behavior change and may not want to consider it any longer.
	Contemplation – stage in which individuals are thinking of making a change soon (i.e., within the next six months).
	Preparation – stage in which individuals are thinking about making a change in the immediate future (i.e., one month) and may have already made some steps in that regard.
	Action – stage in which individuals have started engaging in the new behavior (i.e., within the previous six months).

Theory/ Model	Constructs/ Concepts
	Maintenance – period in which individuals have performed the behavior for at least six months that they are comfortable adding it to their daily routines.

Table reproduced from Contento[50] and Glanz, Rimer & Viswanath[52]

Self-Determination Theory

SDT will be used in this study because it is unique from the afore-mentioned theories in that it focuses on the processes through which people acquire the motivation for initiating a new health-related behavior and sustaining it over time.[43] SDT explicitly identifies autonomy as a human need that when fulfilled, enhances more autonomous forms of behavioral regulations.[53] In contrast to SCT, SDT predicts that both competence and autonomy (volition) are important for behavior adherence.[43] Thus, SDT provides a framework for studying the predictors and outcomes of motivations for health-related behaviors.[53]

According to SDT, social context (environment) influences an individual's intra- and interpersonal growth and motivational differences, and thus, determines the extent to which an individual is self-motivated, energized or integrated in certain situations or cultures.[42] SDT identifies three key psychological needs – autonomy, competence, and relatedness – which, when fulfilled, promotes growth, social development, and personal well-being.[42]

SDT further classifies motivation as autonomous self-regulation, controlled regulation and amotivation, depending on the degree to which the value and regulation of the prescribed behavior emanate from the self.[42,53] Autonomous self-regulation may be motivation derived from the enjoyment arising from the behavior itself (intrinsic motivation), or participating in behaviors that are congruent to people's personal goals or values (integrated regulation), or motivation from the values associated with the behavior (identified regulation).[53] Intrinsic motivation is

undermined by tangible rewards, threats, deadlines, directives, pressured evaluations and imposed goals, but enhanced by choice, acknowledgement of feelings, and opportunities to be self-directed.[42] Controlled motivation may be motivation derived from an external reward, avoidance of punishment or in compliance to social pressures (external regulation) or acting to receive praise or to avoid disapproval or feelings of guilt (introjected regulation).[42] Amotivation refers to 'the state of lacking the intention to act' and could either be due to a person not valuing the activity, not feeling competent enough to carry it out or not expecting it to yield the desired outcome.[42]

Autonomous self-regulation indirectly predicts health behavior change by enhancing perceived competence.[53] According to SDT, an autonomy-supportive health care climate, greater autonomy causality orientation (behavioral regulation) and intrinsic life aspirations facilitate psychological needs satisfaction in health care or health promotion contexts.[53]

To encourage individuals to adopt and maintain health-promoting behaviors, especially those that are not inherently pleasant, it is crucial for them to internalize the proposed behavior (i.e., actively make controlled self-regulation more autonomous by personally endorsing the values associated with the behavior).[53] Relatedness and competence are key to the internalization process because extrinsically motivated behaviors are not generally pleasurable. That is, the prescribed behavior must be modeled or valued by someone the individual feels connected to, and the individual must feel efficacious of doing it.[42] It is also important to understand the nature and dynamics of extrinsic motivation for such individuals.[42]

Exploring how people's social contexts and environmental developments affect their autonomy, competence and relatedness is useful[42], especially in the context of CVD risk assessment because it may provide understanding of why people fail to be screened. For

example, in underserved communities, there is a phenomenon termed predetermination (i.e., a religious term meaning "the ability of a higher power to choose the future path of an individual") that makes individuals less interested or disinterested in seeking medical help.[29] It is characterized by phrases like *"insha' Allah"* (if God wills), "this is my lot in life," and "God is in control." With this mentality, individuals tend to feel that diseases like CVD are beyond their control.[29] Inappropriate risk estimation may lead to increased health disparities/inequalities, increased complications arising from misdiagnoses and reduced cost-effectiveness of screening.[54]

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Chapter 3 - Materials and Methods

Objective 1: Systematic Literature Review

Literature Search

Prior to identifying studies, a search for systematic reviews on "cardiovascular disease risk assessment tools" was done in Cochrane Database of Systematic Reviews, using the *Title Abstract Keyword* option. This yielded 25 Cochrane reviews. This step was necessary to avoid creating a redundant review. We performed a literature search in PubMed and Scopus between May and June 2019 to identify studies published in the English language between 2008 and 2019. The period from 2008 to 2019 was selected to build upon the evidence obtained from a previous systematic review[1], which spanned studies published from January 1, 1999, to February 24, 2009. Search strategy and keywords used followed guidelines outlined in the *COSMIN (COnsensus-based Standards for the selection of health status Measurement INstruments) manual for systematic reviews of Patient-Reported Outcome Measures (PROMs)*[2] as well as those used by Matheny et al.[1] PubMed and MeSH on Demand version 2.0 were used to generate search terms for the search (Table 2). An example of the full search strategy used in the electronic database PubMed is presented in Appendix A.

Table 2. Concept Table for Literature Search

	Cardiovascular disease	**Risk assessment**	**Tool**	**Young adult**	**Vulnerable populations**
MeSH terms/ subheadings	Cardiovascular Diseases	Risk Assessment	Surveys and Questionnaires, Patient Reported Outcome Measures, Health Care Surveys	Young Adult	Vulnerable Populations, Medically Underserved Area
Text words	cardiovascular AND diseases, "cardiovascular diseases", cardiovascular AND disease OR "cardiovascular disease" heart diseases, heart disease, cerebrovascular diseases, hypertension, myocardial ischemia, myocardial infarction, heart attack, cardiovascular stroke, cerebral hemorrhage, cerebral stroke, stroke, brain ischemia	Risk Assessments, Health Risk Assessment, Health Risk Assessments, Risk Factors, risk prediction, risk models, risk prediction models,	Tools, instrumentation, instruments, Community Surveys, Surveys, questionnaires, "surveys and questionnaires," measures, outcomes assessment, outcome measures	young adult, young adults	Disadvantaged, Underserved Patients, Underserved Populations, Sensitive Population Groups, Sensitive Populations, Medically Underserved Population, vulnerable, limited[All Fields] AND health resources[mh]

Eligibility Criteria

Citations and abstracts of all retrieved studies were downloaded to Rayyan for Systematic Reviews (a free web-based tool)[3] and RefWorks citation management software. Duplicate articles were then deleted. Selection for inclusion into the review was done by first screening

titles/abstracts and then reviewing the full text of articles against the inclusion/exclusion criteria. Included studies were required to have: developed and/or used a questionnaire or instrument to assess at least one CVD outcome; developed and validated any tool to assess at least two lifestyle CVD risk factors (i.e., smoking, nutrition behaviors, alcohol use, and physical activity, hereafter referred to as SNAP risk factors) in young adults; reported on CVD risk assessment and/or treatment in people without prior CVD, or in people with and without prior CVD where this information is presented separately; reported on all measures developed and/or used in health promotion studies that aimed to increase CVD risk awareness or prevent CVD by altering one or more SNAP risk factors. The main outcome of interest was objective and/or self-reported measure(s) for the non-clinical assessment of modifiable CVD risk factors by evaluating the SNAP risk factors.

We excluded articles for which no full text was available either through a license at our institution or a general search on the internet. Review/meta-analysis articles were removed from the database before assessing all other articles using our inclusion criteria. Reference lists from retrieved full-text articles were also examined for any other potential studies. Concerning the target age group, articles that did not specify any age range for participants but only stated a median or mean age were excluded because it was difficult to ascertain which age groups were being discussed. On the contrary, if the specified age range fell within the target range of the current study or if analyses were subdivided by age groups, then that article was retained. This review aims to help select or develop an appropriate tool (i.e., non-clinically based) for assessing CVD risk factors in both symptomatic and asymptomatic young adults. Thus, studies that recruit only participants from groups with diagnosed conditions linked to the SNAP risk factors (e.g.,

type 2 diabetes, hypertension) or from specific/special populations (e.g., severe mental illness, eating disorders, elite athletes) were excluded.

Data Extraction

A data extraction form was developed to extract the following information: study details (authors, year, country of origin, and study design [e.g., cross-sectional, cohort, etc.]), participants (study population, characteristics and setting), CVD risk factors (smoking, nutrition, alcohol intake, and physical activity) assessed, CVD risk assessment tools used, and study results/findings. The full list of extracted items is available upon request. Eligible articles were then classified into two groups based on the two objectives: articles related to CVD risk assessment in the general young adult population, and articles concerning assessment in underserved young adults, respectively.

Analyses of Results

Results were summarized by descriptive statistics. A meta-analysis of the identified tools was beyond the scope of this review.

Objective 2: Development of the CVD Questionnaire

Development of the *Need-2-Know* CVD risk questionnaire occurred in three phases: focus group discussion (FGD); item development, and pilot-testing of questionnaire. In the FGD phase, focus groups and key informant interviews assessed participants' health behaviors and knowledge related to CVD. In the item development phase, the emerging themes from the FGD and results from a systematic review were used to generate questionnaire items. In the pilot-testing phase, the test-retest reliability of the designed questionnaire was tested in a nationally representative sample of underserved young adult population. Study procedures were approved by the Kansas State University Institutional Review Board (IRB# 9673).

Phase 1: Focus Group and Key Informant Interviews

Participant Recruitment

Participant recruitment started from April 9 to November 14, 2019. Approximately 316 copies of recruitment flyers were distributed to sixteen locations/organizations that serve most of the general population of Manhattan, Kansas, particularly young adults from low-income families. These institutions were the Boys and Girls Club of Manhattan, Head Start and Early Head Start, Women, Infants, and Children (WIC) Nutrition Services, Manhattan Workforce Center, Manhattan Public Library, Flint Hills Breadbasket and K-State Cat's Cupboard (Kansas State University's food pantry). Additional recruitment avenues were the Mount Zion Family Worship Center, The USD383 Family-In-Transition (FIT) Closet & Clothing Exchange, Goodwill Manhattan, The Salvation Army Family Store and Donation Center, Ascension Via Christi Clinic Primary Care, Westview Church, Konza Prairie Community Health Center, K-State Research and Extension Riley County office, K-State Powercat Financial, K-State Black Student Union and K-State Wellness Coalition. These last three venues were chosen due to convenience since the community-wide recruitment efforts proved quite challenging.

Prior to leaving flyers at the various organizations, permission was sought by the submission of official letters to the responsible contacts of these organizations. Samples of letters and flyer can be found in the Appendix B.

Interested persons then contacted the researcher via email or phone and were given additional information regarding the study purpose and procedures. They were assessed for eligibility by answering brief pre-screening questions (questions regarding age and immigration status). Eligible participants then received a link to complete a brief survey about their time

preference and availability for the 60–90-minute focus group discussion. One of the interested persons was considered ineligible because she did not meet the age requirement.

Upon completion of the survey for availability for FGD, participants were sent an invitation email with the date, time, and place for the FGD session (in the case where a complete set of participants had been reached). Where there were still unfilled slots for FGD session, participants who already completed the survey with their availability were notified that once a full set was available, an invitation email would be sent out for the session. This was necessary so as not to leave the interested participants hanging, as well as ensure a good turnout for the session. Two reminder emails were sent to participants to remind them of the focus group date, time, and location. Those who had requested childcare during the session were also asked to confirm the age and number of children they needed care for. Participants were also contacted via phone a day prior to the scheduled FGD session. These were strategies used to ensure greater likelihood of participants showing up for the sessions.

All participants provided a written informed consent. Participants received a stipend of $30 for participating in the session. Study procedures were approved by the Kansas State University Institutional Review Board (IRB# 9673).

Focus Group/Interview Sessions

The aim of the FGD and interview sessions was to get a better idea of participants' CVD-related behaviors (i.e., smoking, nutrition, alcohol consumption, and physical activity) and their perceptions on regular screening for CVD. A standardized moderator's guide was developed based on a review of the published literature. Prior to conducting the actual FGD, the author was trained by a focus group expert (T.K.) to moderate a mock focus group session with two graduate

researchers and an undergraduate student. Feedback was then provided to help the author improve upon the moderation script and delivery style.

One FGD and four key informant interviews were conducted in Manhattan, Kansas, between June and November 2019. Initially, two FGDs were scheduled; however, except for one participant who had to cancel at the last minute due to travel, most participants in the second set failed to show up. Thus, key informant interviews were included to resolve the difficulties in recruiting participants for an FGD. Except for the number of participants, the key informant interviews followed a similar format as the FGD session. The FGD involved 7 participants and the key informant interviews, a total of 4 participants. The FGD session lasted 1½ h and the interviews, approximately 30 minutes. Sessions were held in a reserved meeting room at the Manhattan Public Library. The public library was chosen for two reasons: - i) it served as a central location for community members, and thus provides reliable access of transportation since not all participants may own cars; ii) it offered a neutral environment, unlike Kansas State University campus, to which some participants may not be very familiar with and might feel intimidated about the environment. The goal was to make the FGD participants as comfortable and relaxed as possible.

The FGD session was facilitated by a moderator and a note-taker. The moderator first welcomed the group to the session, outlining the purpose of the study and study procedures (i.e., rules of participation). The participants were informed that all information shared during the FGD/interview sessions would be kept confidential and that any identifying information, such as name, would be removed from the transcripts to maintain confidentiality. Participants were also made aware that the sessions would be recorded. A *Sony* voice recorder was used in recording, with Zoom cloud recording as a backup. Participants then signed an informed consent.

The discussion then started with the moderator introducing herself and her research team, after which the participants went around the table introducing themselves. Participants were first asked what came to mind when they heard the terms “cardiovascular disease” or “heart disease,” respectively. Concerning the four SNAP risk factors (smoking, nutrition, alcohol consumption, and physical activity), participants were asked questions such as *Please share some reasons why a person might smoke* and *What comes to mind when you hear about alcohol use?* Finally, participants commented on the reasons people should be concerned about heart disease (see moderation guide in Appendix B). At the end of the session, participants completed a demographic form, received their $30 stipend, and the names of participants who expressed an interest in any future discussions were noted.

Focus Group and Interview Transcription, Coding and Analyses

Verbatim transcription was done by the author after each FGD/interview session. Transcripts were then reviewed by the author while listening to the audio-recording and comparing with the note-taker’s field notes to ensure completeness of the interviews. The transcribed files were then stored on a secured computer server and retrieved later for analyses.

Two graduate researchers (A.O.A. and Y.W.) independently coded each transcript manually and came to a consensus regarding final code allocation. A third coder (T.K.) was consulted to resolve any conflicting coding. First, open coding was used to identify the themes or categories within the data. Axial coding was then used to confirm the fit between the codes and concepts stated in the FG/interviews by exploring the relationship between codes.[4] Significant quotes or statements were highlighted, and notes made in the margins to arrange and organize data. Saliency or significance of the codes were determined by frequency of discussion within and across sessions.

Phase 2: Item Development

Emergent themes from the focus group held in phase one and results from a systematic review of the literature on existing CVD risk assessment tools in young adult populations guided initial questionnaire item development. The WHO STEPs manual,[5] one of the non-clinical-based CVD risk assessment tool identified from the systematic review, and the Basic Psychological Needs Satisfaction Scale[6] served as a framework for developing items related to the four SNAP risk factors (i.e., smoking, nutrition, alcohol consumption, and physical activity behaviors) and psychological needs satisfaction, respectively. The SNAP risk factors were chosen to be consistent with the main CVD risk factors discussed in the focus groups and key informant interviews conducted in phase 1 because participants had shared their thoughts on factors influencing these 4 risk factors.

The initial item pool consisted of 86 items divided into five sub-scales measuring SNAP risk factors, basic psychological needs satisfaction, (assessing the three basic components of the SDT- autonomy, competence, and relatedness), personal medical history, health insurance coverage and demographic items. The initial questionnaire draft was then reviewed by a panel of doctoral committee members who were experts in chronic diseases, health behaviors, consumer behaviors and health communication, for representativeness, appropriateness, and relevance of the items. The panel evaluated the items for clarity and conciseness and suggested alternative wording or ways of capturing items for easy understanding by respondents.

The final *Need-2-Know* CVD risk assessment questionnaire included a total of 59 items: 35 items in the Behavioral Risk Factor subscale, 9 items in the Basic Psychological Needs Satisfaction subscale, 5 items in the Personal Medical History subscale, an item in the Type of Health Insurance subscale, and 9 items in the Demographic subscale (Appendix C). The average

time for completion of the questionnaire was approximately 9 minutes. Readability statistics were computed using the Microsoft Word function in Windows 10 and the reading level identified as 7th grade. The response format for the questionnaire included frequency and a 5-point Likert scale ranging from 1 (*Not at all true*) to 5 (*Very much true*). All responses also included a *"Prefer not to answer"* option.

Behavioral Risk Factors

This subscale assessed the four SNAP behaviors, namely tobacco use (9 items), alcohol consumption (4), diet (15 items), and physical activity (7 items). The items assessing tobacco use included five questions about general smoking habits, two questions on smokeless tobacco- *Do you currently use any smokeless tobacco products* and *How often do you use smokeless tobacco products?* and two questions on electronic vapor products– *Have you ever used an electronic vapor product?* and *During the past 30 days, on how many days did you use an electronic vapor product?* The diet questions, adapted from the WHO STEPs manual[5] and the Dietary Screener Questionnaire which also included 4 items on dietary salt, assessed participants' intake of various kinds of food and drinks during the past month. Response options included a 5-point Likert scale ranging from 1 (*Always*) through 5 (*Never*). The items on physical activity were adapted from the short form of the International Physical Activity Questionnaire (IPAQ)[7] and assessed how often participants engaged in vigorous and moderate physical activities, walking, and sitting within a week. Frequency of activity was given in days per week and duration in hours and minutes. Total minutes of daily activity was calculated by first converting the hours to minutes and then adding to the minutes given.

Basic Psychological Needs Satisfaction

This subscale assessed the three basic psychological needs according to the SDT – autonomy (3 items), competence (3 items), and relatedness (3 items). Beginning with a common stem, *In my life, I feel …*, participants endorsed nine statements including *that my choices are based on my true interests and values*; *that I successfully complete difficult tasks and projects*; and *a sense of contact with people who care for me, and whom I care for*. The response option was a 5-point Likert scale ranging from 1 (*Not at all true*) to 5 (*Very much true*). A score for each need was obtained by averaging all 3 items in each subset of the 3 needs.

Personal Medical History, Health Insurance Type, and Demographic subscales

The Personal Medical History subscale examined participants' history of heart disease, heart attack/stroke, high blood pressure, type 2 diabetes, and cancer. One item assessed the type of health insurance participants had. Demographic items included age, gender, ethnicity, race, level of education, employment status and the type of health care they visited.

Phase 3: Pilot Study

Participants

A pilot study helps to narrow down an initial large set of possible questionnaire items using the target audience.[8] The purpose of this pilot-test was to examine the test-retest reliability of the *Need-2-Know* risk assessment questionnaire. A nationally representative sample of respondents was recruited through the "Purchasing Respondents" (or Panels) service feature available through *Qualtrics*. The use of a representative sample was necessary to enhance the validity and generalizability of the questionnaire. To be eligible, respondents had to be between 18 and 34 years old and willing to take surveys. Additionally, a quota of 55% was set as the maximum proportion of sample self-identified as a racial minority (i.e., non-white and

Hispanic/Latino) to be included. A sample size of 200 respondents was determined based on the following estimation:

$$Sample\ size = (z - score)^2 \text{ x } std\ dev \text{ x} \frac{(1 - std\ dev)}{(margin\ of\ error)^2}$$

Where z-score is the z-score for the selected confidence interval (i.e., 95%); std dev = standard deviation (i.e., the expected variance in responses); and margin of error = the expected error to allow in sampling target population. The z-score for a 95% confidence interval is 1.96. Assuming a standard deviation of 0.5 and margin of error of 7%:

$$\therefore Sample\ size = (1.96)^2 \text{ x } 0.5 \text{ x } \frac{(1 - 0.5)}{(0.07)^2} = 196$$

The questionnaire was launched twice due to a failed first attempt. In March 2021, *Qualtrics* sent out an invitation to its panel to participate in the survey. Two hundred and twenty participants responded. Three weeks later, this same panel was recontacted for a retest. Unfortunately, only 2 people responded because they had not been previously informed about re-contacting in future. The researchers met with the *Qualtrics* team to discuss the next steps. Upon consultation with their statisticians, a new sample size of 333 participants was agreed upon to ensure a good response rate at the retest. The second launch of questionnaire occurred in May 2021. A new *Qualtrics* panel was invited to participate in the survey. Respondents completed questionnaire three weeks apart; this time frame was chosen to prevent any carryover effects between time. Three hundred and thirty-three respondents completed the initial survey and 103 of them completed the second survey. Only respondents for whom data was available at both test and retest were used for the test-retest reliability analysis (i.e., N = 103).

All participants gave written informed consent prior to participation and received a stipend of $5 each time they participated.

Data Analysis

Internal consistencies of survey subscales were assessed by Cronbach's coefficient alpha (categorical data) and two-way mixed effects model of intraclass correlation coefficient (ICC, continuous data). The two-way mixed effects model ICC assumes fixed effects of the rater and random effects of the subject. Categorical variables included smoking status, smokeless tobacco use, and electronic vapor product use; frequency of standard alcoholic drink consumption during past 12 months; all items on the Diet subscale; psychological needs subscale items; personal medical history items; and type of health insurance. Continuous variables comprised the physical activity items. To evaluate test-retest reliability for each individual item on the questionnaire, Pearson's and Spearman's correlation coefficients were calculated for continuous variables, while Cohen's weighted kappa was used for categorical variables. Pearson's correlation was performed for normally distributed data and Spearman's rank test for non-normally distributed data.

Descriptive statistics were used to characterize study participants according to demographic factors (i.e., age, gender, race, ethnicity, medical history, and level of education). For continuous variables, means and standard deviations were calculated whereas, categorical variables were analyzed with frequency distributions.

A two-way multivariate analysis of variance (MANOVA) was used to test significant racial, ethnic and gender differences among participants across the psychological needs scale subscales.

Statistical significance for all analyses was determined by p-value <0.05. All statistical analyses were performed using SPSS software (Version 27.0, IBM Corp, Armonk, NY, 2020).

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Chapter 4 - Tools for Assessing Cardiovascular Disease Risk Factors in Underserved Young Adult Populations: A Systematic Review (Manuscript)

Abstract

Cardiovascular disease (CVD, i.e., disease of the heart and blood vessels) is a major cause of death globally. Current assessment tools use either clinical or non-clinical factors alone or in combination to assess CVD risk. The aim of this review was to critically appraise, compare, and summarize existing non-clinical-based tools for assessing CVD risk factors in underserved young adult (18–34-year-old) populations. Two online electronic databases - PubMed and Scopus - were searched to identify existing risk assessment tools, using a combination of CVD-related keywords. Search was limited to articles available in English only and published between 2008 and 2019. Of the 10,383 studies initially identified, 67 were eligible. Five out of the 67 articles assessed CVD risk in underserved young adult populations. A total of 21 distinct CVD risk assessment tools were identified; six of these did not require clinical or laboratory data in their estimation (i.e., non-clinical). This review provides a summary of non-clinical-based CVD risk assessment tools used in the general young adults and underserved young adult populations.

Keywords: non-clinical; risk assessment; underserved; young adult

1. Introduction

Between 2017 and 2018, approximately 42% of United States adults aged ≥ 20 years were obese, with approximately 9% falling in the class 3 (extreme or severe) obesity category [1]. Obesity is a risk factor for cardiovascular disease (CVD, i.e., disease of the heart and blood vessels), diabetes, and related health conditions such as coronary heart disease (CHD), heart failure, and stroke [2]. CHD is the narrowing of the inner walls of the blood vessels that transport blood to the heart (arteries) due to a build-up of a waxy substance (plaque), and is the number one cause (45.1%) of CVD-related deaths in the U.S., with stroke (16.5%) and high blood pressure (9.1%) being the next two highest [3,4]. Globally, CVD is the leading cause of death, and in the U.S., it is estimated that one in every three deaths is attributable to CVD [3,5]. It is further projected that by 2030, about 23.6 million deaths will result from CVD events [3].

Cardiovascular risk assessment is necessary for effective CVD prevention intervention, especially in high-risk individuals [6]. Early screening in youth is encouraged to prevent cardiovascular events in adulthood as current evidence suggests that CVD risk factors are even present in adolescence [7]. To date, both paper-based and electronic risk scores have been clinically applied to estimate absolute risks using patients' data and published equations. Current risk assessment tools either use family medical history (FH) alone or in combination with clinical factors (e.g., cholesterol level, blood pressure, and glucose level) or non-clinical factors (e.g., gender, race, weight, height, dietary and physical activity) to assess disease risk. However, there are some limitations to these tools including non-representative or historically dated populations, limited ethnic representation, and narrowly defined and unreliable endpoints [8].

CVD risk scores or algorithms (equations) originated for use in disease diagnoses by health care practitioners, but they could also be used in public health settings as health promotion

tools [9]. A non-clinical- or non-laboratory-based assessment tool is particularly useful and a cost-effective option in limited-resource settings, where access to clinical samples or factors may be challenging [10,11]. Further, in resource-deficient, ethnic minority and/or underserved communities, where members have less or no health insurance coverage; higher cost barriers to health care access; and poor self-rated general health, disease diagnoses with a family health history or clinical tool may be elusive. Thus, until an illness becomes life-threatening, it may be difficult to detect it and even attempt to control it [12,13]. Previous reviews have identified and evaluated the accuracy of available tools to assess cardiovascular risk factors in the general adult populations [14-18]. For example, Gaziano et al. [18] compared nonblood-based and blood-based total cardiovascular risk scores in seven countries and concluded that in terms of performance, both types of risk scores equally predicted risk in the cohorts studied. Chamnan et al. [17] also evaluated the performance of available CVD risk scores used among patients with diabetes and found differences between risk scores originally developed in these individuals compared to those developed in the general population. A recent review by Sacramento et al. [14] described available methods and assessment tools for the population at high risk of CVD. However, a summary of available CVD risk assessment tools, specifically in young adults, is lacking.

Thus, the primary aim of this review is to critically appraise, compare, and summarize existing non-clinical-based tools for assessing CVD risk factors in young adult populations, particularly underserved young adults. Specifically, the objectives were to summarize: 1) the instruments/questionnaires used to assess lifestyle CVD risk factors (i.e., smoking, nutrition behaviors, alcohol use, and physical activity, hereafter referred to as SNAP risk factors) in young

adult populations (18–34-year-old); 2) the existing instruments to assess risk factors in young adults from underserved populations.

2. Methods and Methods

2.1. Search Strategy

To avoid creating a redundant review, an initial search for systematic reviews on "cardiovascular disease risk assessment tools" was done in Cochrane Database of Systematic Reviews. This yielded 25 Cochrane reviews. A literature search was performed by one of the researchers (A.A.O.A.) in PubMed and Scopus between May and June 2019 to identify studies published in the English language between 2008 and 2019. The period from 2008 to 2019 was selected to build upon the evidence obtained from a previous systematic review [15], which spanned studies published from January 1, 1999, to February 24, 2009. Search strategy and keywords used followed guidelines outlined in the COSMIN (Consensus-based Standards for the selection of health status Measurement Instruments) manual for Systematic Reviews of Patient-Reported Outcome Measures (PROMs) [19] as well as those used by Matheny et al. [15]. PubMed and MeSH on Demand version 2.0 were also used to generate a concept table (Table 1) and search terms for the search.

2.2. Eligibility Criteria

Citations and abstracts of all retrieved studies were downloaded to Rayyan for Systematic Reviews (a free web/mobile application; https://www.rayyan.ai/) [20] and RefWorks Citation Manager (version 2.1.0.1). Duplicate articles were then deleted. Selection for inclusion into the review was done by first screening titles/abstracts and then reviewing the full text of articles against the inclusion/exclusion criteria. Included studies were required to have: developed and/or used a questionnaire or instrument to assess at least one CVD outcome; developed and validated

any tool to assess at least two SNAP risk factors in young adults or underserved young adults; reported on CVD risk assessment and/or treatment in people without prior CVD, or in people with and without prior CVD where this information is presented separately; or reported on all measures developed and/or used in health promotion studies that aimed to increase CVD risk awareness or prevent CVD by altering one or more SNAP risk factors. The main outcome of interest was objective and/or self-reported measure(s) for the non-clinical assessment of modifiable CVD risk factors by evaluating the SNAP risk factors.

We excluded articles for which no full text was available either through a license at our institution or a general search on the internet. Review/meta-analysis articles were removed from the database before assessing all other articles using our inclusion criteria. Reference lists from retrieved full-text articles were also examined for any other potential studies. Concerning the target age group, articles that did not specify any age range for participants but only stated a median or mean age were excluded because it was difficult to ascertain which age groups were being discussed. On the contrary, if the specified age range fell within the target range of the current study or if analyses were subdivided by age groups, then that article was retained. This review aims to help select an appropriate tool (i.e., non-clinically based) for assessing CVD risk factors in both symptomatic and asymptomatic young adults. Thus, studies that recruited only participants from groups with diagnosed conditions linked to the SNAP risk factors (e.g., type 2 diabetes, hypertension) or from specific/special populations (e.g., severe mental illness, eating disorders, elite athletes) were excluded.

2.3. Data Extraction

A data extraction form (Table S1) was developed to extract the following information: study details (authors, year, country of origin, and study design [e.g., cross-sectional, cohort,

etc.]), participants (study population, characteristics, and setting), CVD risk factors (smoking, nutrition, alcohol intake, and physical activity) assessed, CVD risk assessment tools used, and study results/findings. Eligible articles were then classified into two groups based on the two objectives.

2.4. Analyses of Results

Results were summarized by descriptive statistics. A quantitative synthesis of the identified tools was beyond the scope of this review.

3. Results

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow chart of the study selection process is presented in Figure 1. The initial search identified a total of 10,383 studies which was further limited to full text and abstracts, narrowing the total down to 367 articles. Overall, 67 articles were eligible, 5 of which assessed CVD risk in underserved young adult populations (Figure 1).

3.1. Studies Assessing CVD Risks in the General Young Adult Population

Table 2 presents a summary of the included articles that used non-clinical tools to assess CVD risk factors in the general young adult population, including the studies that had young adults only as sub-group analysis of a broader age range of adults.

3.1.1. Study Designs and Study Populations

Most (n = 40, 64 %) of the included studies were cross-sectional in design (Figure 2). The study populations comprised healthy individuals from both general adult and young adult populations. Almost one-third (n = 19, 30.6 %) of the included studies' participants were within the 18–44 and 20-49 years age ranges.

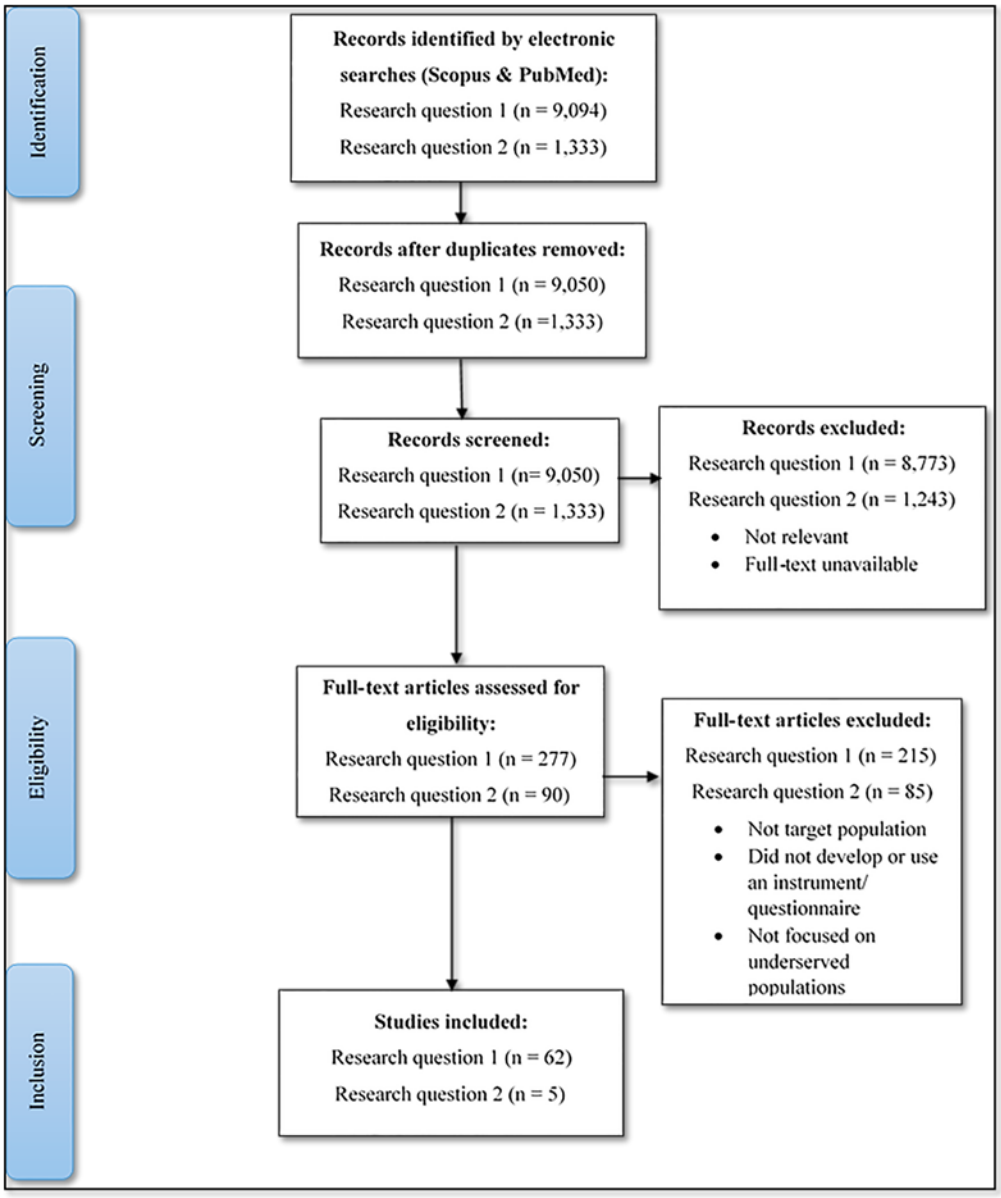

Figure 1. PRISMA Flow Chart of Electronic Database Search

3.1.2. CVD Outcomes

Assessed CVD outcomes included the prevalence of CVD risk factors (e.g., total cholesterol, high-density lipoprotein cholesterol, and low-density lipoprotein cholesterol), hypertension, FH of CVD/CHD, presence of metabolic syndrome, diabetes, CHD risk, ideal cardiovascular health (ICH) index, perception of heart disease risk, awareness of lifestyle risk factors, and knowledge of CHD. About half of the studies (n = 30, 48 %) assessed at least two

SNAP risk factors, including six articles that assessed all four SNAP risk factors [21-26]. The most commonly assessed risk factor was smoking (n = 46, 74 %), followed by physical activity (n = 33, 53 %) and/or nutrition/diet (n = 17, 27 %).

Table 1. Concept Table for the Literature Search

	Cardiovascular disease	**Risk assessment**	**Tool**	**Young adult**	**Vulnerable populations**
MeSH terms/ subheadings	Cardiovascular Diseases	Risk Assessment	Surveys and Questionnaires, Patient Reported Outcome Measures, Health Care Surveys	Young Adult	Vulnerable Populations, Medically Underserved Area
Text words	cardiovascular AND diseases, "cardiovascular diseases", cardiovascular AND disease OR "cardiovascular disease" heart diseases, heart disease, cerebrovascular diseases, hypertension, myocardial ischemia, myocardial infarction, heart attack, cardiovascular stroke, cerebral hemorrhage, cerebral stroke, stroke, brain ischemia	Risk Assessments, Health Risk Assessment, Health Risk Assessments, Risk Factors, risk prediction, risk models, risk prediction models,	Tools, instrumentation, instruments, Community Surveys, Surveys, questionnaires, "surveys and questionnaires," measures, outcomes assessment, outcome measures	young adult, young adults	Disadvantaged, Underserved Patients, Underserved Populations, Sensitive Population Groups, Sensitive Populations, Medically Underserved Population, vulnerable, limited[All Fields] AND health resources[mh]

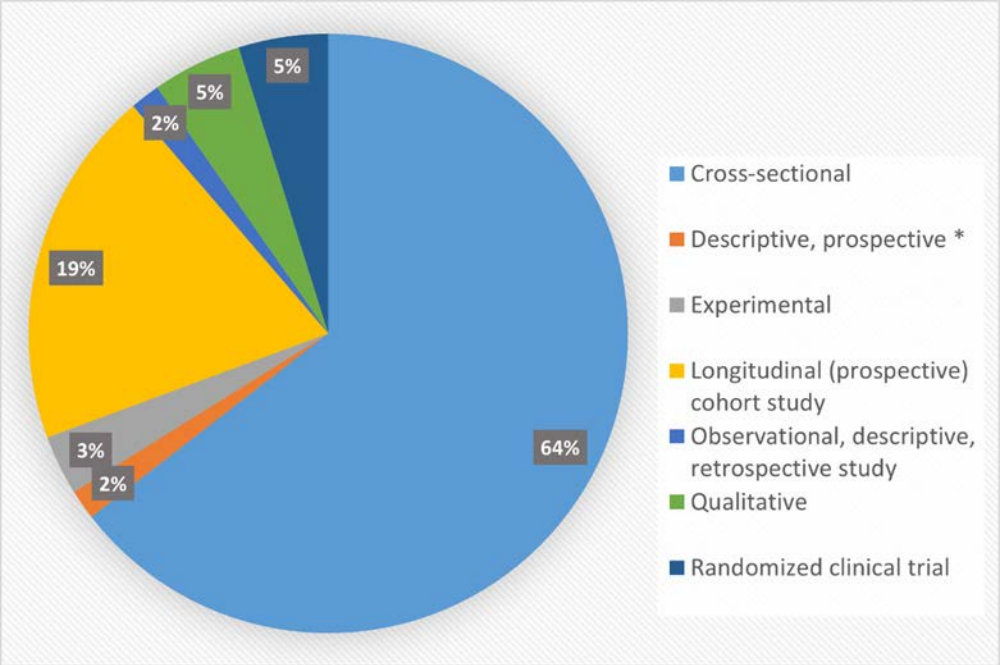

Figure 2. Distribution of Included Studies by Study Designs [Note: *Qualitative Study]

Table 2. Summary of Included Studies that Used Non-clinical Tools for Risk Assessment in the General Young Adult Population

No.	Author(s); year of publication	Study population	Country	Sample size	Age (years)	Gender	Modifiable CVD risk factors assessed (smoking, nutrition/diet, alcohol use, or physical activity)	Risk assessment measure/ tool
1	Williamson W et al. 2018 [27] [72]	Young adults without clinical evidence of cerebrovascular disease	U.K	125	18 - 40	49 % female	Smoking, alcohol use, physical activity	Detailed questionnaire on medical history, socioeconomic status, and self-reported behaviors such as nutritional intake, smoking, and alcohol consumption.
2	Tran D-T et al. 2016 [28] [73]	College students at a Midwestern institution	U.S. A	100	19-39	Male & female*	None	Heart Disease Fact Questionnaire; The Health Beliefs Related to Cardiovascular Disease
3	Thorpe RJ et al. 2016 [29] [74]	Participants from 2000–2009 National Health Interview Surveys	U.S. A	619,130	18-75+	52.1 % female	Physical activity	Health survey
4	Lai HL et al. 2015 [30] [75]	East Carolina University undergraduates	U.S. A	525	16-23	60.7 % female	Smoking, physical activity	Health survey (internally validated)
5	Mark AE et al. 2014 [31] [76]	Individuals at risk for coronary heart disease	U.S. A	388	22-78	60.6 % female	Nutrition/diet	Questionnaire (the Healthy Eating Opinion Survey)

6	Bloomfield GS et al. 2013 [21] [77]	Adults [Health and Demographic Surveillance System]	Kenya	4,037	18 - >64	61 % female	Smoking, nutrition/diet, alcohol use, physical activity	Home-based survey using the WHO STEPwise approach to chronic disease risk factor surveillance (WHO STEPS)
7	Schmitz R et al. 2012 [32] [78]	Non-institutionalized adult population (National health interview [GEDA 2009] respondents.	Germany	21,262	18 - ≥65	51.5 % female	Nutrition/diet, physical activity	Self-reported physician-diagnosed disease
8	Koura MR et al. 2012 [33] [79]	Young adult females	Saudi Arabia	370	Mean = 19.9 ±1.4	100 % female	Smoking, nutrition/diet, physical activity	WHO-STEPS
9	Baragou S et al. 2012 [23] [80]	The general adult population	Togo	2,000	18 – 98	55.1 % female	Smoking, nutrition/diet, alcohol use, physical activity	WHO STEPS
10	Foulds HJA et al. 2012 [34] [81]	Aboriginal adult population (participants from the Hearts in Training and Health Beat physical activity training programs)	Canada	882	16 – 77	75.2 % female	Smoking, physical activity	Multiple choice questions
11	Chan CW et al. 2012 [35] [82]	Hong Kong Chinese population	Hong Kong	236	18 – 91	66.5 % female	None	Survey
12	Maniadakis N et al. 2011 [36] [83]	General adult population	Greece	3,007	18 - >65	51.7 % female	None	Survey
13	Al Hamarneh YN et al. 2011[25] [84]	General adult population	Northern Ireland	1,000	20 – 79	46 % females	Smoking, nutrition/diet, alcohol use, physical activity	Questionnaire

14	Kuklina EV et al. 2010 [37] [85]	Participants from the National Health and Nutrition Examination Survey (NHANES)	U.S. A	2,587	20 -35 (male); 20 - 45 (female)	61.2 % female	Smoking	Survey
15	Wamala JF et al. 2009 [38] [86]	Adult population	Uganda	842	20 - >75	48 % female	Smoking, alcohol use, physical activity	Questionnaire
16	Bjartveit K et al. 2009 [39] [87]	Individuals surveyed for CVD risk factors	Norway	48,682	20 – 49	51.6 % female	Smoking, physical activity	Questionnaire
17	Tucker AM et al. 2009 [40] [88]	Veteran football players	U.S. A	504	23 – 35	100 % male	Smoking	Survey instrument
18	Sanderson SC et al. 2009 [26] [89]	Respondents from the Office of National Statistics Omnibus Survey	U. K	1,747	16 – 75	47 % female	Smoking, nutrition/diet, alcohol use, physical activity	Questionnaire
19	Jamil H et al. 2009 [41] [90]	Respondents from the Health Assessment Survey	U.S. A	3,280	18 – 75	71.9 % female	Smoking, nutrition/diet, physical activity	Health survey
20	Ammouri AA et al. 2008 [42] [91]	General population	Jordan	295	15 – 75	51 % female	None	Questionnaire (The Perception of Risk of Heart Disease Scale)

*Gender distribution not stated in article. [Note: A survey is a method of data collection and analysis whereas a questionnaire is a tool or instrument used to collect data; a questionnaire may be a subset of a survey.]

3.1.3. Risk Assessment Tools/Models/Measures

A total of 21 distinct CVD risk assessment tools were identified from the 62 articles; six of these did not require clinical or laboratory data in their estimation (i.e., non-clinical).

The non-clinical-based tools were mostly questionnaires or health surveys and included the Heart Disease Fact Questionnaire (HDFQ), the Health Beliefs Related to CVD-Perception measure (HBCVD), the Healthy Eating Opinion Survey, the Perception of Risk of Heart Disease Scale (PRHDS) and the WHO STEPwise approach to chronic disease factor surveillance (i.e., the STEPS instrument).

The identified clinical-based tools were the 10-year and 30-year Framingham Risk Score (FRS), Atherosclerotic CVD (ASCVD) risk calculator, Pathobiological determinants of atherosclerosis in youth (PDAY) risk score, the Korean coronary CHD risk score, HellenicSCORE, the AHA Ideal Cardiovascular Health (IDEAL) metrics, the Progetto CUORE equation, the Framingham CHD Prediction Score tool, the HeartScore, Framingham risk equations (Joint British Societies 2 [JBS2] risk calculator) and the Systematic COronary Risk Evaluation (SCORE). The FRS was the most common CVD risk assessment tool used in the young adult population.

3.1.4. Sample Size

The number of participants in each of the included studies ranged from 15 to 619,130 (median = 2,000).

3.2. Studies Assessing CVD Risks in Underserved Young Adult Population

Only five articles were related to CVD risk assessment in underserved young adult populations, and these originated from the U.S. (Table 3.).

3.2.1. Study Designs and Study Populations

The included articles comprised two cross-sectional studies, two longitudinal studies, and a qualitative (descriptive) study. Except for the qualitative study, the study population fell within the targeted age range (18–34 years, Table 3). Regarding study populations, all but one study used data from national surveys.

3.2.2. CVD Outcomes

Assessed CVD outcomes included the prevalence of CVD risk factors, cardiometabolic disease risk, perception of CVD risk, and history of CHD risk factors. Only one [43] out of the five articles assessed all four SNAP risk factors (Table 3).

Table 3. Summary of Included Studies that Used Non-clinical Tools for Risk Assessment in Underserved Young Adult Population

No.	Author(s); year of publication	Study population	Country	Sample size	Age (years)	Gender	Modifiable CVD risk factors assessed (smoking, nutrition/diet, alcohol use, or physical activity)	Risk assessment measure/ tool
1	Doom JR et al. 2017 [43] [92]	Add Health study participants	U.S. A	14, 493	24–34	48.9 % female	Smoking, nutrition/diet, alcohol use, physical activity	30-year Framingham CVD Risk Score
2	Abshire DA et al. 2016 [44] [93]	Undergraduate Caucasian males recruited from a public, 4-year university through purposive and snowball sampling; free of CVD and not enrolled in a health-related major.	U.S. A	10	18–25	100 % male	None	Interview guide
3	Wickrama KAS et al. 2016 [45] [94]	Add Health study participants	U.S. A	8,824	24–32	Male & female*	None	None; biomarkers assessed
4	Khan RJ et al. 2015 [46] [95]	1997 - 2004 data from National Health Interview Survey	U.S. A	121,284	18–44	54.5 % female	Smoking, physical activity	None

5	Jamil H et al. 2009 [41] [90]	Respondents from the Health Assessment Survey	U.S. A	3,280	18–75	71.9 % female	Smoking, nutrition/diet, physical activity	Health survey

*Gender distribution not stated in the article.

3.2.3. Risk Assessment Tools/Models/Measures

The 30-year Framingham CVD Risk score was the only identified clinical-based CVD risk assessment tool. Non-clinical-based tools were mostly surveys and questionnaires.

3.2.4. Sample Size

The number of participants in each of the included studies ranged from 10 to 121,284 (median = 6,052).

4. Discussion

This systematic literature review aimed to critically appraise, compare, and summarize existing non-clinical-based tools for assessing CVD risk factors in young adult populations, particularly underserved young adults. Results showed that most risk assessment tools used in the young adult population were clinical-based and included what have been and are still used in middle-aged and older adults, with the FRS tool being the most common one. Additionally, a modified version of the FRS, the 30-year FRS tool, was identified as an assessment tool in a study involving underserved young adults [43]. Unlike the original 10-year FRS, the 30-year FRS tool predicts an individual's risk of developing CVD within 30 years and was specifically designed to be used in the young adult population [47].

The STEPS instrument was developed by the WHO for collecting data and measuring non-communicable disease (NCD) risk factors in three sequential levels or "steps" – questionnaire, physical, and biochemical measurements [48]. It includes a core, an expanded, and optional components that provide a framework for countries conducting NCD risk factor surveys, and allows each country to choose which of the three steps it will implement [48]. Steps 1 and 2 require non-clinical data, whereas step 3 depends on clinical data; thus, the STEPS instrument could be used as either a clinical- or non-clinical risk assessment tool.

The non-clinical-based tools identified differed from the five non-laboratory-based cardiovascular risk assessment algorithms identified in a previous review [49] – the Framingham non-laboratory-based, Gaziano non-laboratory-based, the WHO/International Society of Hypertension (WHO/ISH) non-laboratory-based algorithms, the Swedish consultation-based method, and the United Kingdom (UK) General Practice model. The Framingham non-laboratory-based algorithm uses office-based predictors that are obtained in primary care (i.e., age, body mass index [BMI], systolic blood pressure, antihypertensive medication use, current smoking, and diabetes status) to predict 10-year CVD risk [50]. The Gaziano non-laboratory-based algorithm predicts CVD events using age, sex, smoking, diabetes, systolic blood pressure, antihypertensive medication use, and BMI [51]. The WHO/ISH algorithms predict 10-year cardiovascular risk using easily measurable variables such as gender, systolic blood pressure, smoking status, type 2 diabetes mellitus, and total serum cholesterol [52]. The Swedish consultation-based method predicts cardiovascular risk using age, sex, current smoking, prevalence of diabetes or hypertension at baseline, blood pressure, waist-to-height ratio, and family history of CVD. The UK General Practice model uses age, systolic blood pressure, smoking habit, and self-rated health to predict 10-year CVD risk in older women [53].

Unlike previously identified tools, the non-clinical-based tools identified in this review either assessed an individual's knowledge or perception of heart disease risk. They did not directly assess one's CVD risk in relation to the four SNAP risk factors. For example, the HDFQ is a validated and reliable 25 true/false-item questionnaire developed to assess heart disease knowledge among individuals with diabetes [54]. Each questionnaire item is a specific recommendation from at least one of three organizations – the American Diabetes Association, the American Heart Association, and the National Diabetes Education Program. Since the HDFQ

assesses heart disease knowledge in people with diabetes, it is heavily skewed on diabetes-related CHD risk factors. Thus, further testing of its predictive validity is required for other health behaviors like healthy eating, self-monitoring of blood glucose, or CHD diagnosis [54].

The HBCVD has been used to assess the perceptions of cardiovascular risk factors among individuals with type 2 diabetes. This is a 25-item questionnaire that assesses four constructs of the Health Belief Model (HBM), namely perceived susceptibility and severity of CVD, and benefits and barriers to diet and exercise [55]. However, further reliability testing of this tool is proposed.

The Healthy Eating Opinion Survey is a 43-item questionnaire assessing the psycho-social influences on dietary behavior in individuals at risk for CHD [31]. It was developed based on the Theory of Planned Behavior and assesses one's intention (5 items), attitude toward the behavior (6 items), subjective norm (6 items), perceived behavioral control (5 items), behavior belief (10 items), normative belief (5 items), and control belief (6 items).

The PRHDS is a 20-item instrument developed to measure an individual's perception of his/her heart disease risk in three dimensions – "dread risk," (perceived lack of control, dread, catastrophic potential, and fatal consequences) "risk," (a hazard with few, moderate, known outcomes and consequences) and "unknown risk" (hazards judged to be observable, unknown, new, and delayed in their manifestation of harm) [42].

Timely identification of young adults at high risk for CVD will help reduce risk factor burden [56]. However, the selected age range in this review (i.e., 18–34 years) differs from that of the samples used in previous studies. For example, Alssema et al. [9] used a sample of adults aged 28–85 years to develop a single non-laboratory-based model for predicting three cardio-metabolic diseases– CVD, type 2 diabetes, or chronic kidney disease in three different

population cohorts. Additionally, in the study by Jamil et al. [41], the 18–39 years age group was least represented; thus, the authors suggested using a relatively younger sample to make findings more generalizable.

Furthermore, the five previously mentioned non-laboratory-based risk assessment tools relied on varied samples of middle-aged and older adults [49]. For instance, the Framingham non-laboratory-based algorithm was derived from an adult sample aged 30–74 years [50]; the Gaziano non-laboratory-based algorithm used an ethnically and racially diverse sample of 25–74-year-old adults [18,51]; the Swedish consultation-based method was derived from a sample of Swedish adults aged 40–59 years; and the UK General Practice model used only women aged 60–79 years [52]. Further validation of these non-laboratory-based tools in diverse populations is recommended to improve their performance and applicability in the screening and management of CVD in limited-resource settings [49].

Considering the non-clinical risk assessment tools identified in this review were developed to assess CVD risks, none assessed all four SNAP risk factors together. The knowledge assessed with HDFQ pertained to smoking, healthy eating and physical activity in relation to heart disease as well as the relationship between diabetes and heart disease. Unlike the HDFQ, the HBCVD and the PRHDS do not assess a specific health behavior in relation to CVD risk, but an individual's health beliefs in a likely CVD event and CVD risk perceptions, respectively. It was not surprising that smoking was the most commonly assessed SNAP risk factor in the included studies, considering most of the existing CVD risk scores use an individual's smoking status as a predictor in their calculations [14,16]. An individual's knowledge and perception may provide some useful information about an individual's behavior

but may not necessarily predict their CVD risk. Thus, incorporating all four SNAP risk factors in a CVD risk assessment tool may provide a broader picture of disease risk.

4.1. Strengths and Limitations

A major strength of the present review is that it used a concept table in combination with a previously used search strategy that was thorough enough to identify the existing tools in adult populations. To the best of our knowledge this is the first systematic review to identify tools or instruments that have been used to assess CVD risk factors in the young adult population. However, there are a few limitations. The number of articles excluded due to full-text unavailability might have caused an indirect omission of relevant details, especially from studies published in other languages. The grey literature was not searched; this could have also been a good place to find other non-laboratory-based risk assessment tools.

5. Conclusions

This review provides a summary of non-clinical-based CVD risk assessment tools used in the general young adults and underserved young adult populations. Generally, there were only a few objective and/or self-reported measure(s) for the non-clinical assessment of modifiable CVD risk factors among young adults. Future studies could adapt items from the identified non-clinical-based CVD risk assessment tools, incorporating the four SNAP risk factors to develop a risk assessment tool, and validate it in young adults.

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Chapter 5 - Development and Reliability Testing of the *Need-2-Know* Cardiovascular Disease Risk Assessment Questionnaire: A Pilot Study

Abstract

Objective

Develop and establish the test-retest reliability of the *Need-2-Know* cardiovascular disease (CVD) risk assessment questionnaire.

Design

A mixed-methods study design was used, comprising focus groups, interviews, and test-retest reliability testing.

Participants

Nationally representative young adult (aged 18–34 years) sample across the U. S.

Main Outcome Measures: Tobacco use, alcohol use, dietary habits, physical activity, basic psychological needs satisfaction scores (autonomy, competence, and relatedness).

Analysis

Descriptive statistics used to characterize participants. Internal consistency of questionnaire items was assessed with Cronbach's alpha (categorical data) and two-way mixed effects model of intraclass correlation coefficients (ICC, continuous data). Test-retest reliability was assessed with Pearson's correlation or Spearman's rank test for continuous variables and Cohen's weighted kappa for categorical variables.

Results

The intraclass correlation coefficient (ICC) for subscale items ranged from 0.224 to 0.680 across subscales. Cohen's weighted Kappa (κ_w) ranged from 0.184 to 0.851 and were mostly significant ($p<0.001$). The test-retest correlation coefficients ranged from 0.037 to 0.736 for items in the Tobacco use subscale; 0.471 to 1.000 for the Alcohol use items; 0.337 to 0.664 for Diet items; 0.098 to 0.726 for PA items; and 0.601 to 0.724 for the psychological needs satisfaction.

Conclusions and Implications for Research and Practice

The test-retest reliability of the *Need-2-Know* CVD risk questionnaire showed good reliability for three out of its six subscales (PA, psychological needs, and diet). Its reliability can further be tested and improved by testing it in other young adult populations. The study attrition rate of 30% could also be improved in future studies by using recruitment methods that will ensure a high return rate.

Key Words: non-clinical; chronic disease; instrument; reliability scale

Introduction

Two major causes of death in the U.S. are heart disease and stroke.[1] Risk factors such as smoking, hypertension, type 2 diabetes, high levels of LDL-cholesterol, and low cardiorespiratory (i.e. relating to the heart, lungs, and blood vessels) fitness increase CVD risk.[1] Towards its goal to improve the cardiovascular health of Americans by 20% by reducing CVD and stroke-related death by 20%, the American Heart Association (AHA) developed the *ideal cardiovascular health* (ICH) concept. ICH is defined as "the presence of both ideal health behaviors (non-smoking, body mass index <25 kg/m^2, physical activity at goal levels, and

pursuit of a diet consistent with guideline recommendations) and ideal health factors (untreated total cholesterol <200 mg/dL, untreated blood pressure <120/<80 mm Hg, and fasting blood glucose <100 mg/dL)."[2]

Our systematic literature review identified non-clinical-based CVD risk assessment tools used in general young adults as well as in underserved young adult populations. Results indicated that there were only a few objective and/or self-reported measure(s) for the non-clinical assessment of modifiable CVD risk factors (i.e., smoking, nutrition behaviors, alcohol use, and physical activity, hereafter referred to as SNAP risk factors) among young adults. It was recommended that future studies adapted items from the non-clinical-based CVD risk assessment tools identified, incorporating the four SNAP risk factors to develop a risk assessment tool, and validate it in young adults. Thus, the overall goal of developing and designing of the *Need-2-Know* CVD risk questionnaire is to provide a non-clinical means of assessing CVD risk in underserved young adult populations. The *Need-2-Know* CVD risk questionnaire will have a motivational component. According to the self-determination theory (SDT), social context (environment) influences an individual's intra- and interpersonal growth and motivational differences, and thus, determines the extent to which an individual is self-motivated, energized or integrated in certain situations or cultures.[3] SDT identifies three key psychological needs – autonomy, competence, and relatedness – which, when fulfilled, promotes growth, social development and personal well-being as well as facilitates intrinsic motivation.[3]

Exploring how people's social contexts and environmental developments affect their autonomy, competence and relatedness is useful[3], especially in the context of CVD risk assessment because it may provide understanding of why people fail to be screened. For example, in underserved communities, there is a phenomenon termed predetermination (i.e., a

religious term meaning "the ability of a higher power to choose the future path of an individual") that makes individuals less interested or disinterested in seeking medical help. It is characterized by phrases like *"insha' Allah"* (if God wills), "this is my lot in life," and "God is in control." With this mentality, individuals tend to feel that diseases like CVD are beyond their control.[4] Inappropriate risk estimation may lead to increased health disparities/inequalities, increased complications arising from misdiagnoses and reduced cost-effectiveness of screening.[5]

When designing a questionnaire, it is important to bear the respondents in mind, by identifying characteristics that may enable them to provide the best answer or hinder them from doing so. Respondents' ability and willingness to answer questions are greatly influenced by various design features, thereby determining how accurately they answer questions.[6] For self-administered questionnaires, the absence of an interviewer makes it necessary to motivate respondents by providing accurate instructions, and a good layout and format of questions.[7] According to Parmenter and Wardle,[7] the interpretability (i.e., the ability to understand or make meaning) of a questionnaire is enhanced by using simple questions, avoiding negatively phrased questions as well as double-barreled questions (i.e., asking two questions in the same sentence). An instrument or questionnaire is reliable if it produces consistent or stable scores of a construct or measure over time (test-retest reliability), across items (internal consistency), and across different raters or researchers (inter-rater reliability).[8,9]

The purpose of this pilot-test was to establish the test-retest reliability of the *Need-2-Know* CVD risk assessment questionnaire. It was hypothesized that this questionnaire would be a reliable measure for researchers to use to assess CVD risk in young adults. Results from this pilot study will also provide baseline data prior to the designing of nutrition education programs as part of CVD risk assessment efforts in underserved young adult populations.

Methods

Development of the *Need-2-Know* CVD risk questionnaire occurred in three phases: focus group discussion (FGD); item development, and pilot-testing of questionnaire. In the FGD phase, focus groups and key informant interviews assessed participants' health behaviors (i.e., smoking, nutrition, alcohol use, and physical activity behaviors) and knowledge related to CVD. In the item development phase, the emerging themes from the FGD and results from a systematic review were used to generate questionnaire items. In the pilot-testing phase, the test-retest reliability of the designed questionnaire was tested in a nationally representative sample of underserved young adult population. Study procedures were approved by the Kansas State University Institutional Review Board (IRB# 9673).

Phase 1: Focus Group and Key Informant Interviews

Participant Recruitment

Participant recruitment started from April 9 to November 14, 2019. Approximately 316 copies of recruitment flyers were distributed to sixteen locations/organizations that serve most of the general population of Manhattan, Kansas, particularly young adults from low-income families. These institutions included the Boys and Girls Club of Manhattan, Head Start and Early Head Start, Women, Infants, and Children (WIC) Nutrition Services, Manhattan Workforce Center, Manhattan Public Library, Flint Hills Breadbasket and K-State Cat's Cupboard (Kansas State University's food pantry).

Prior to leaving flyers at the respective organizations, permission was sought by the submission of official letters to the responsible contacts of these organizations. Samples of letters and flyer can be found in the Appendix B.

Interested persons then contacted the researcher via email or phone and were given additional information regarding the study purpose and procedures. They were assessed for eligibility by answering brief pre-screening questions (questions regarding age and immigration status). Eligible participants then received a link to complete a brief survey about their time preference and availability for the 60–90-minute focus group discussion. One of the interested persons was considered ineligible because she did not meet the age requirement.

Upon completion of the survey for availability for FGD, participants were sent an invitation email with the date, time, and place for the FGD session (in the case where a complete set of participants had been reached). Where there were still unfilled slots for FGD session, participants who already completed the survey with their availability were notified that once a full set was available, an invitation email will be sent out for the session. This was necessary so as not to leave the interested participants hanging, as well as ensure a good turnout for the session. Two reminder emails were sent to participants to remind them of the focus group date, time, and location. Those who had requested childcare during the session were also asked to confirm the age and number of children they needed care for. Participants were also contacted via phone a day prior to the scheduled FGD session. These were strategies used to ensure greater likelihood of participants showing up for the sessions.

All participants provided written informed consent. Participants received a stipend of $30 for participating in the session.

Focus Group/Interview Sessions

The aim of the FGD and interview sessions was to get a better idea of participants' CVD-related behaviors (i.e., smoking, nutrition, alcohol consumption, and physical activity or SNAP risk factors) and their perceptions on regular screening for CVD. A standardized moderator's

guide was developed based on a review of the published literature. Prior to conducting the actual FGD, the author was trained by a focus group expert (T.K.) to moderate a mock focus group session with two graduate researchers and an undergraduate student. Feedback was then provided to help the author improve upon the moderation script and delivery style.

Overall, one FGD (7 participants) and four key informant interviews (4 participants) were conducted in Manhattan, Kansas, between June and November 2019. Key informant interviews were included to make up for the difficulties in recruiting participants for an FGD. Except for the number of participants, the key informant interviews followed a similar format as the FGD session. The FGD session lasted 1½ h and the interviews, approximately 30 minutes. Sessions were held in a reserved meeting room at the Manhattan Public Library. The public library was chosen because: - i) it served as a central location for community members, and thus provides reliable access of transportation since not all participants may own cars; ii) it offered a neutral environment, unlike Kansas State University campus, which some participants may not be very familiar with and might feel intimidated about the environment. The goal was to make the FGD participants as comfortable and relaxed as possible.

The FGD session was facilitated by a moderator and a note-taker. The moderator first welcomed the group to the session, outlining the purpose of the study and study procedures (i.e., rules of participation). The participants were also informed that all information shared during the FGD/interview sessions would be kept confidential and that any identifying information, such as name, would be removed from the transcripts to maintain confidentiality. Participants were also made aware that the sessions would be recorded. A *Sony* voice recorder was used in recording, with Zoom cloud recording as a back-up. Participants then signed an informed consent. The

discussion then started with the moderator introducing herself and her research team, after which the participants went around the table introducing themselves.

Participants were first asked what came to mind when they heard the terms "cardiovascular disease" or "heart disease," respectively. Concerning the four SNAP risk factors (smoking, nutrition, alcohol consumption, and physical activity), participants were asked questions such as *Please share some reasons why a person might smoke* and *What comes to mind when you hear about alcohol use?* Finally, participants recommended reasons people should be concerned about heart disease (see moderation guide in Appendix B). At the end of the session, participants completed a demographic form, received their $30 stipend, and the names of participants who expressed an interest in any future discussions were noted.

Focus Group and Interview Transcription, Coding and Analyses

Verbatim transcription was done by the author after each FGD/interview session. Transcripts were then reviewed by the author while listening to the audio-recording and comparing with the note-taker's field notes to ensure completeness of the interviews. The transcribed files were then stored on a secured computer server and retrieved later for analyses.

Two graduate researchers (A.O.A. and Y.W.) independently coded each transcript manually and came to a consensus regarding final code allocation. A third coder (T.K.) was consulted to resolve any conflicting coding. First, open coding was used to identify the themes or categories within the data. Axial coding was then used to confirm the fit between the codes and concepts stated in the FG/interviews by exploring the relationship between codes.[10] Significant quotes or statements were highlighted, and notes made in the margins to arrange and organize data. Saliency or significance of the codes were determined by frequency of discussion within and across sessions.

Phase 2: Item Development

Emergent themes from the focus group held in phase one and results from a systematic review of the literature on existing CVD risk assessment tools in young adult populations guided initial questionnaire item development. The WHO STEPs manual,[11] one of the non-clinical-based CVD risk assessment tool identified from the systematic review, and the Basic Psychological Needs Satisfaction Scale[12] served as a framework for developing items related to the four SNAP risk factors (i.e., smoking, nutrition, alcohol consumption, and physical activity behaviors) and psychological needs satisfaction, respectively. The SNAP risk factors were chosen to be consistent with the main CVD risk factors discussed in the focus groups and key informant interviews conducted in phase 1 because participants had shared their thoughts on factors influencing these 4 risk factors.

The initial item pool consisted of 86 items divided into five sub-scales measuring SNAP risk factors, basic psychological needs satisfaction, (assessing the three basic components of the SDT- autonomy, competence, and relatedness), personal medical history, health insurance coverage and demographic items. The initial questionnaire draft was then reviewed by a panel of doctoral committee members who were experts in chronic diseases, health behaviors, consumer behaviors and health communication, for representativeness, appropriateness, and relevance of the items. The panel evaluated the items for clarity and conciseness and suggested alternative wording or ways of capturing items for easy understanding by respondents.

The final *Need-2-Know* CVD risk assessment questionnaire included a total of 59 items: 35 items in the Behavioral Risk Factor subscale, 9 items in the Basic Psychological Needs Satisfaction subscale, 5 items in the Personal Medical History subscale, an item in the Type of Health Insurance subscale, and 9 items in the Demographic subscale (Appendix C). The average

time for completion of the questionnaire was 9 minutes. Readability statistics were computed using the Microsoft Word function in Windows 10 and the reading level identified as 7th grade. The response format for the questionnaire included frequency and a 5-point Likert scale ranging from 1 (*Not at all true*) to 5 (*Very much true*). All responses also included a *"Prefer not to answer"* option. For questions that were not applicable to participants, skip logic was utilized to bypass questions.

Behavioral Risk Factors

This subscale assessed the four SNAP behaviors, namely tobacco use (9 items), alcohol consumption (4), diet (15 items), and physical activity (7 items). The items assessing tobacco use included five questions about general smoking habits, two questions on smokeless tobacco- *Do you currently use any smokeless tobacco products* and *How often do you use smokeless tobacco products?* and two questions on electronic vapor products– *Have you ever used an electronic vapor product?* and *During the past 30 days, on how many days did you use an electronic vapor product?* The diet questions which also included 4 items on dietary salt, assessed participants' intake of various kinds of food and drinks during the past month. Response options included a 5-point Likert scale ranging from 1 (*Always*) through 5 (*Never*). The items on physical activity assessed how often participants engaged in vigorous and moderate physical activities, walking, and sitting within a week.

Basic Psychological Needs Satisfaction

This subscale assessed the three basic psychological needs according to the SDT – autonomy (3 items), competence (3 items), and relatedness (3 items). Beginning with a common stem, *In my life, I feel …*, participants endorsed nine statements including *that my choices are based on my true interests and values*; *that I successfully complete difficult tasks and projects*;

and *a sense of contact with people who care for me, and whom I care for*. The response option was a 5-point Likert scale ranging from 1 (*Not at all true*) to 5 (*Very much true*).

Personal Medical History, Health Insurance Type, and Demographic Subscales

The Personal Medical History subscale examined participants' history of heart disease, heart attack/stroke, high blood pressure, type 2 diabetes, and cancer. One item assessed the type of health insurance participants had. Demographic items included age, gender, ethnicity, race, level of education, employment status and the type of health care they visited.

Phase 3: Pilot Study

Participants

A pilot study helps to narrow down an initial large set of possible questionnaire items using the target audience.[7] The purpose of this pilot-test was to examine the test-retest reliability of the *Need-2-Know* CVD risk assessment questionnaire. A nationally representative sample of respondents was recruited through the "Purchasing Respondents" (or Panels) service feature available through *Qualtrics*. The use of a representative sample was necessary to enhance the validity and generalizability of the questionnaire. To be eligible, respondents had to be between 18 and 34 years old and willing to take surveys. Additionally, a quota of 55% was set as the maximum proportion of sample self-identified as a racial minority (i.e., non-white and Hispanic/Latino) to be included. A sample size of 200 respondents was determined based on the following estimation:

$$Sample\ size = (z - score)^2 \text{ x } std\ dev \text{ x } \frac{(1 - std\ dev)}{(margin\ of\ error)^2}$$

Where z-score is the z-score for the selected confidence interval (i.e., 95%); std dev = standard deviation (i.e., the expected variance in responses); and margin of error = the expected error to

allow in sampling target population. The z-score for a 95% confidence interval (CI) is 1.96. Assuming a standard deviation of 0.5 and margin of error of 7%:

$$\therefore Sample\ size = (1.96)^2 \text{ x } 0.5 \text{ x } \frac{(1-0.5)}{(0.07)^2} = 196$$

The questionnaire was launched twice due to a failed first attempt. In March 2021, *Qualtrics* (Provo, Utah) sent out an invitation to its panel to participate in the survey. Two hundred and twenty participants completed the initial survey. Three weeks later, this same panel was recontacted for a retest. Unfortunately, only 2 people responded because they had not been previously informed about re-contacting in future. The researchers met with the *Qualtrics* team to discuss the next steps. Upon consultation with their statisticians, a new sample size of 333 respondents was agreed upon to ensure a good response rate at the retest. The second launch of questionnaire occurred in May 2021. A new *Qualtrics* panel was invited to participate in the survey. Respondents completed questionnaire three weeks apart; this time frame was chosen to prevent any carryover effects between time. Three hundred and thirty-three respondents completed the initial survey and 103 of them completed the second survey. Only respondents for whom data was available at both test and retest were used for the test-retest reliability analysis (i.e., N = 103).

All participants gave written informed consent prior to participation and received a stipend of $5 each time they participated.

Data Analysis

Internal consistencies of survey subscales were assessed by Cronbach's coefficient alpha (categorical data) and two-way mixed effects model of intraclass correlation coefficient (ICC, continuous data). The two-way mixed effects model ICC assumes fixed effects of the rater and random effects of subject. Categorical variables included smoking status, smokeless tobacco use,

and electronic vapor product use; frequency of standard alcoholic drink consumption during past 12 months; all items on the Diet subscale; psychological needs subscale items; personal medical history items; and type of health insurance. Continuous variables comprised the physical activity items. To evaluate test-retest reliability for each individual item on the questionnaire, Pearson's and Spearman's correlation coefficients were calculated for continuous variables, while Cohen's weighted kappa was used for categorical variables. Pearson's correlation was performed for normally distributed data and Spearman's rank test for non-normally distributed data.

Descriptive statistics were used to characterize study participants according to demographic factors (i.e., age, gender, race, ethnicity, medical history, and level of education). For continuous variables, means and standard deviations were calculated whereas, categorical variables were analyzed with frequency distributions.

A two-way multivariate analysis of variance (MANOVA) was used to test significant racial, ethnic and gender differences among participants across the psychological needs scale subscales.

Statistical significance for all analyses was determined by p-value <0.05. All statistical analyses were performed using SPSS software (Version 27.0, IBM Corp, Armonk, NY, 2020).

Results

Focus Group and Interviews

Participant Characteristics

A total of 11 participants took part in the focus groups– seven in the full group discussion and four key informant interviews. Participants were primarily female (72.7%, n=8) with an average age of 25.3±4.8 years and a range from 20 to 33 years. The majority were white (54%, n=6), followed by African American (36.4%, n=4), and Asian (9.1%, n=1). Almost 30% (n=3) of

participants had at least a high school education diploma. About half (54%, n=6) of the participants reported earning less than $25,000 per year.

Emerging Themes

Most participants cited heart problems and improper functioning of the heart as what comes to mind when they hear the term “cardiovascular diseases.” A participant referred to heart disease as “a worm in heart”:

“Worm in heart” … Yeah. Like, like one of those um worms type of bugs that people put in their system to make themselves skinny but in this case, a worm gone into your heart. (Male, 26 years).

When discussing the risk factors for heart disease, the most prominent risk factors mentioned across FGs were the role of diet/eating habit and lifestyle in the development and/or prevention of heart disease. Specifically, participants mentioned that eating fruits and vegetables (e.g., “leafy things”) and less processed foods reduce heart disease risk. Participants also cited excessive salt and fats, palm oil, egg yolk, fast food, and whole milk as being unhealthy or harmful to heart health. Time, cost, and convenience were most cited as factors that prevent people from eating healthy.

“It’s much it’s much easier and cheaper to eat processed foods, than it is to eat um unprocessed foods. … It's cheaper to make your own lunch than go buy your lunch, but the amount of time you have to spend making your lunch in the morning or the night before. Um say like 10, 20 minutes, whereas you can spend a minute, two minutes purchasing in a restaurant, in a restaurant or food vendor”; “… even it's a lot easier to go get a McDonald's hamburger um than like a very nice salad.” (Male, 20 years)

When asked what could encourage or prevent people from eating healthy or exercising, participants cited factors such as lifestyle, environment, cost/affordability, accessibility, time, knowledge, and motivation.

"Yeah I know, well at least for me, like, I mean, I know what I should eat. I know that what I shouldn't. But honestly, like I think or for me, it depends I guess kind of related to what XXX said the people who are who are around you. Um for example, like if you're with someone who really motivates you to eat healthy, you will probably eat healthy. Well, it's not his fault, but my husband, um [laughs] does not motivate and might sound like. Let's go get a ( ) donut. Probably not. I mean they are like only $4 at Walmart for, like, 12 or we probably shouldn't get it. And he's like, "I mean if you want, let's get it". And I'm like you're supposed to tell me no so like it's easier if you have someone" (Female, 28 years)

"So going back to the educational piece, I know that there's been um, a few studies done that I've read that you can educate a handful of people on how to eat and how to prepare something. But if they don't have the actual tools to do it, then they they won't bring it into their home. Um, so I think that's just the barrier so motivating yourself, if you don't actually have physical um tools in your household to eat and prepare your food. You won't…" (Female, 25 years)

"I think with what she what XXX said and XXX resonated with me, both because I think you have to be intrinsically motivated to want to change anything. So you would have to figure out what motivates that person, whether if it's if like if somebody told me, like, think about your life in this many years you're gonna have 2 children, if you don't, you know, do eat better, you know, get healthier, you're not gonna be able to be a part of that. That would really, you know, sit with me and they think about, you know, the choices that I'm making for myself and them, but

with the like you can get all the information you want you can get information every single day."

(Female, 25 years)

Many participants indicated that they were unaware of any community resources that address heart diseases. They also recommended the doctor's office as a good avenue to provide information or resources related to heart diseases.

In response to what they thought is the best way to provide information on heart disease, participants expressed a need for more prevention outreach and awareness. A participant recommended less usage of strategies such as fear appeal/tactics, but instead to emphasize on the positives of maintaining a healthy lifestyle. Age was also mentioned in all the sessions; some also indicated targeting children/youth so they can adopt such behaviors early on in life.

Instrument Development and Design

Internal consistency

The Cronbach's alpha (α) values for the diet, physical activity and psychological needs satisfaction subscales fell within the acceptable range (≥ 0.70). The α values were 0.81 for the 3-item autonomy and competence subscales and 0.82 for relatedness. The overall 9-item psychological needs satisfaction subscale had an α of 0.91. Excluding an item (i.e., question about the kind of milk consumed in the past month) from the diet subscale yielded an α = 0.86 for the remaining 10 items on the subscale. The milk question was excluded because its response categories or options were different from the other items on the diet subscale. The Cronbach's α for that individual milk question could not be calculated because single item cannot have an α computed. The α values were 0.68 for the dietary salt items (N=3) and 0.37 for some items on the alcohol use (N=4) and smoking subscale (N=3). The 5-item personal medical history subscale had an α of 0.70.

The intraclass correlation coefficient (ICC) for all three composite scores of the psychological needs satisfaction subscale was 0.68 (95% CI, 0.63–0.73). ICC for days spent doing PA was 0.22 (95% CI, 0.12–0.347); 0.48 (95% CI, 0.36–0.59) for total daily PA minutes across the 3 categories; 0.47 (95% CI, 0.36–0.58) for weekly MET-minutes per day of PA; and 0.60 (95% CI, 0.49–0.70) MET-minutes per week of all 3 types of PA and combined weekly MET-minutes of PA. Based on the 95% CI of the ICC estimate, the internal consistency of the questionnaire items is interpreted as follows: <0.5 (poor consistency); 0.5–0.75 (moderate consistency); 0.75–0.90 (good consistency); and >0.90 (excellent consistency).[13] The psychological needs satisfaction subscale (composite scores) showed moderate consistency whereas the items on the physical activity subscale showed poor to moderate consistency.

Pilot Study

Participant Characteristics

Only data from the second launch (relaunch) of the survey were used in this study. A total of 333 respondents completed the questionnaire the first time and 103 of them returned for the retest. The attrition rate was approximately 31%. A summary of demographic characteristics at initial test (baseline) is presented in Table 4. Mean age of participants was 29.3 (SD=4.0) years and a range from 18 to 34 years. The median age was 30 years. Almost two-third (61.3%) of the respondents were female. Respondents were predominantly white (58.6 %) and 15% were Black/African American. Although 5% preferred to not report income, 58% of the respondents reported earning more than $50,000 per year.

Table 4. Demographic Characteristics of Respondents at Baseline

Characteristic	**Total [n (%)]**
Gender	
Female	204 (61.3)
Male	129 (38.7)
Hispanic/Latino	
Yes	69 (20.7)
No	262 (78.7)
I don't know	1 (0.3)
PNA	1 (0.3)
Race	
American Indian/Alaskan Native	7 (2.1)
Asian	55 (16.5)
Black/African American	50 (15.0)
Native Hawaiian/Other Pacific Islander	2 (0.6)
White	195 (58.6)
Other	16 (4.8)
Prefer not to answer	8 (2.4)
Highest level of education	
Less than high school	7 (2.1)
High school degree or equivalent (e.g., GED)	27 (8.1)
Some college but no degree	51 (15.3)
Associate degree/Technical school graduate	40 (12.0)
Bachelor's degree	134 (40.2)
Graduate degree	72 (21.6)
Other	1 (0.3)
PNA	1 (0.3)
Annual household income	
$0 to $9,999	24 (7.2)
$10,000 to $24,999	42 (12.6)
$25,000 to $49,999	57 (17.1)
$50,000 and above	193 (58.0)
PNA	17 (5.1)
Type of health insurance coverage	
None/Unsure/PNA	68 (20.4)
Medicare/Medicaid or Private or Other	264 (79.3)

At least 2 types of insurance	1 (0.3)
Abbreviations: PNA = Prefer not to answer	

Behavioral Risk Factors

Most respondents (65%) had never smoked and 20% of respondents currently smoke. Fourteen percent of respondents reported being previous smokers. Smoking duration ranged from 1 to 22 years for current smokers with a mean of 7.86 (SD=5.53) years. The mean smoking duration for previous smokers was 6.53 (SD=5.06) years. Approximately 22% of respondents reported being current smokeless tobacco products users with most (76.4%) using smokeless tobacco products at least 3 days per week. Approximately, 35% reported ever using electronic vapor products; mean frequency of use of electronic vapor product was 3.04 (SD=1.68) days per week.

About half of respondents (56.2%) reported consuming one standard alcoholic drink at least a day per week. Approximately 22% of respondents reported having stopped drinking due to health reasons.

The modal frequency of consumption of dark green, red, and orange vegetables, starchy vegetables, fruit, whole-grain foods, dairy foods, and red meat was 3–4 times per week; 2–3 times per week for cooked legumes; and 2 times per week for other vegetables and sugary snacks and dessert. The proportion of respondents reporting these frequencies ranged from 15 to 21%.

The median vigorous MET-minutes/week, moderate MET-minutes/week, and walking MET-minutes/week were 1920.00 (i.e., 240 minutes/week or 4 h/week), 720.00 (i.e., 180 minutes/week or 3 h/week), and 792.00 (i.e., 240 minutes/week or 4 h/week), respectively. The median total PA MET-minutes/week was 2290.50.

Basic Psychological Needs Satisfaction

The mean autonomy, competence, and relatedness scores were 3.88 (SD=0.86), 3.87 (SD=0.86) and 3.88 (SD=0.87), respectively and the median score for each item was 4.00 (i.e., respondents rated themselves as very true regarding their feelings for autonomy, competence, and relatedness).

Health Insurance Type and Source of Health Information

Most respondents (79.3%) indicated they had health insurance coverage.

Sixty-one percent of respondents obtained their health information from one of six options – family doctor or other medical professional, family or friends, mass media, internet, print media, and Churches or community groups. Thirty-five percent of respondents obtained their health information from a minimum of 2 sources.

Test-retest Reliability

Test-retest reliability analysis were performed on data obtained from the second launch of the *Qualtrics* survey; only respondents for whom data was available from both initial test and retest were used (i.e., N=103). The results from the test-retest reliability analysis are summarized in Tables 5 and 6. Correlation coefficients ranged from 0.037 to 0.736 for items in the Tobacco use subscale; 0.471 to 1.000 for the Alcohol use items; 0.337 to 0.664 for Diet items; 0.098 to 0.726 for PA items; and 0.601 to 0.724 for the psychological needs satisfaction. Even though most of the correlation coefficients for Diet and PA subscales were significant, they showed unacceptable to poor reliability. This suggests that the scores of the items were unstable across the two times.

Cohen's weighted Kappa (κ_w) ranged from 0.184 to 0.851 and were mostly significant (Table 6). Depending on whether the items on the psychological needs satisfaction subscale was

considered a continuous or categorical score, its test-retest reliability changed. The κ_w (Table 6) were relatively smaller than the correlation coefficients (Table 5).

Table 5. Spearman's Rho and Pearson's Coefficient for Continuous Items.

Item/ Question	**N**	**Coefficient**
Tobacco use		
How long have you been smoking? 1 Number of years __	7	0.164
On average, how many of the following products do you smoke **each day/week?**		
1 Manufactured cigarettes (Daily) 2 Hand-rolled cigarettes (Daily) 3 Pipes full of tobacco (Daily) 4 Cigars (Daily) 5 Prefer not to answer	13	0.540 0.143 0.179 0.472 0.736**
1 Manufactured cigarettes (Weekly) 2 Hand-rolled cigarettes (Weekly) 3 Pipes full of tobacco (Weekly) 4 Cigars (Weekly)	13	0.293 -0.008 0.037 0.340
How long did you smoke? 1 Number of years __	9	0.404
How often do you **use smokeless tobacco** products?	14	0.494
During the past 30 days, on how many days did you use an **electronic vapor product**?	26	r =0.581**
Alcohol Use		
During the past 12 months, **how frequently** have you had at least one standard alcoholic drink?	57	r =0.471**

Thinking about the **past 7 days**. How many standard drinks did you have each day? 1 Monday _____ 2 Friday _____ 3 Saturday _____	3 4 2	r = 0.982 r = 0.892 r = 1.000**
Diet		
During the past month, how often did you eat cooked or raw **dark-green, red, and orange vegetables**, such as green leafy or lettuce salad, spinach, kale, tomatoes, red peppers, carrots, and sweet potatoes?	100	r = 0.475**
During the past month, how often did you eat cooked **legumes** (beans and peas) such as refried beans, baked beans, beans in soup, pork and beans or any other type of cooked dried beans? Do **not** include green beans or green peas.	100	r = 0.543**
During the past month, how often did you eat **starchy vegetables** such as white potatoes, corn, green beans, plantains, and cassava?	100	r = 0.465**
During the past month, how often did you eat **other vegetables** (not including leafy green salads, potatoes, or cooked dried beans)?	100	r = 0.436**
During the past month, how often did you eat **fruit** (include fresh, frozen, canned, dried or 100% fruit juices)? Do **not** include fruit-flavored drinks.	100	r = 0.664**
During the past month, how often did you eat **whole-grain** foods such as whole-wheat bread, whole-grain cereals and crackers, oatmeal, quinoa, popcorn, and brown rice? Do **not** include white bread and white rice.	100	r = 0.487**
During the past month, how often did you have dairy foods? Include milk, cheese, and cheese products.	100	r = 0.402**
During the past month, how often did you eat **red meat**, such as beef, pork, ham, or sausage?	100	r = 0.354**

Do **not** include chicken, turkey, or seafood. Include red meat you had in sandwiches, lasagna, stew, and other mixtures. *Red meats may also include veal, lamb, and any lunch meats made with these meats.*		
During the past month, how often did you drink sugar-sweetened beverages (i.e., drinks to which sugar has been added) such as **regular soda or pop, sweetened** coffee and tea**, sweetened** fruit drinks, sports or energy drinks, and flavored water? Examples: *Arizona* Iced Tea, Frappuccino, *Kool-Aid*, lemonade, *Hi-C*, cranberry drink, *Gatorade*, *Red Bull* or Vitamin Water. Do **not** include diet soda, tea or drinks or artificially sweetened coffee or drinks.	100	r = 0.449**
During the past month, how often did you eat sugary snacks and desserts, including **candies**, **doughnuts**, sweet rolls, Danish, muffins, pan dulce, pop-tarts, **cookies, cake, pie, brownies**, **ice cream or other frozen desserts**? Do **not** include sugar-free products.	100	r = 0.337**
Physical activity		
During the **last 7 days**, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling? 1 _____**days per week**	34	0.615**
How much time did you usually spend doing **vigorous** physical activities on one of those days? (Total vigPA minutes)	19	0.525**
Weekly vigorous PA MET-minutes		0.371
During the **last 7 days**, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do **not** include walking.	26	0.610**
How much time did you usually spend doing **moderate** physical activities on one of those days? (Total modPA minutes)	18	0.098
Weekly moderate PA MET-minutes		0.512*

During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?	41	0.648**
How much time did you usually spend **walking** on one of those days? (Total walking minutes)	25	0.418*
Weekly walking MET-minutes	24	0.292
During the **last 7 days**, how much time did you spend **sitting** on a **weekday**? (Total sitting minutes)	27	0.726**
Psychological needs satisfaction (scores)		
Autonomy	100	r = 0.601**
Competence	100	r = 0.724**
Relatedness	100	r = 0.633**

**Correlation coefficient is significant at the 0.01 level (2-tailed).

*Correlation coefficient is significant at the 0.05 level (2-tailed).

r = Pearson's coefficient; unspecified = Spearman's rho.

Table 6. Cohen's Weighted Kappa Coefficients for Categorical Items.

Item/ Question	**Coefficient**
Tobacco Use	
Regarding tobacco smoking, please choose which one applies to you.	0.851*
During the past 12 months, have you tried to **stop smoking**?	0.581*
Do you **currently use any smokeless tobacco** products [such as snuff, chewing tobacco, chew, dip]? *Smokeless tobacco products are placed in the mouth or nose.* **Do not count any electronic vapor products.**	0.731*
Have you ever used an electronic vapor product?	0.770*
Alcohol use	
Have you consumed any alcohol within the **past 12 months**?	0.764*

Have you stopped consuming alcohol due to health reasons, such as a negatively impacting your health or because of your doctor or other health worker's advice?	0.494*
Diet	
During the past month, what kind of milk did you usually drink?	0.523*
Dietary salt	
How often do you **add salt or a salty sauce such as soy sauce** to your food right before you eat it or as you are eating it?	0.438*
How often is **salt, salty seasoning or a salty sauce added** in cooking or preparing foods in your household?	0.483*
During the past month, how often did you eat any **processed meat**, such as bacon, lunch meats, or hot dogs? Include processed meats you had in sandwiches, soups, pizza, casseroles, and other mixtures.	0.485*
How much **salt or salty sauce** do you think you consume?	0.318*
Psychological needs satisfaction	
1 2 3 4 5 Not at all Very much	
That my choices are based on my true interests and values.	0.467*
Free to do things my own way.	0.446*
That my choices express my "true self".	0.466*
That I successfully complete difficult tasks and projects.	0.469*
That I take on and master hard challenges.	0.441*
Very capable in what I do.	0.481*
A sense of contact with people who care for me, and whom I care for.	0.358*
Close and connected with other people who ae important to me.	0.332*
A strong sense of intimacy with the people I spend time with.	0.425*
Personal medical history	

Heart disease	0.184*
Heart attack/stroke	0.215*
High blood pressure	0.557*
Type II diabetes	0.290*
Cancer	0.438*
Health insurance type	
Weighted K and related statistics could not be computed because each variable has less than 2 valid categories.	

*κ_w coefficient is significant at the 0.05 level (2-tailed).

Racial, ethnic, and gender differences across the psychological needs' subscale

The two-way MANOVA results indicated that there was no significant interaction effect of race, ethnicity, and gender among participants across the psychological needs scale subscales $F(6, 612) = 1.844$, $p = 0.088$; Wilks' $\Lambda = 0.965$). However, there was a significant interaction effect of ethnicity and gender $F(3, 306) = 2.855$, $p = 0.037$; Wilks' $\Lambda = 0.973$) and ethnicity and race $F(18, 866) = 2.217$, $p = 0.003$; Wilks' $\Lambda = 0.880$).

Discussion

The aim of this pilot study was to develop and evaluate the test-retest reliability of a non-clinical CVD risk assessment questionnaire (i.e., the *Need-2-Know* CVD risk questionnaire). The development of the questionnaire involved three phases: focus group discussion (FGD); item development, and pilot-testing of questionnaire.

Overall, one FGD and four key informant interviews were conducted in Manhattan, Kansas, between June and November 2019. The emergent themes from conducted focus groups and interviews informed on the behavioral risk factors to include in the questionnaire. When discussing the risk factors for heart disease, the most prominent risk factors mentioned across FGs were the role diet/eating habit and lifestyle played in the development and/or prevention of

heart disease. Participants also cited time, cost and accessibility as factors that could hinder one from eating healthy or exercising. A participant also cited motivation as something that could encourage or prevent someone from eating healthy or exercising. This was interesting because part of the rationale for developing a new CVD risk assessment questionnaire was to incorporate a motivational component to help understand peoples CVD-related behaviors. Most of the participants also reported being unaware of any community resources that could educate them about heart disease.

The initial instrument development phase was guided by findings from a systematic review of the literature on existing CVD risk assessment tools in young adult populations. One non-clinical CVD risk assessment tool that was identified from the systematic review was the WHO STEPs for surveillance of non-communicable disease.[141] This instrument and the Basic Psychological Needs Satisfaction Scale[154] served as a framework for developing items related to the four SNAP behaviors (i.e., smoking, nutrition, alcohol consumption, and physical activity behaviors) and need satisfaction, respectively.

Cronbach's α is the most common measure of internal consistency; α ≥0.80 is considered as good internal consistency.[8] In other cases, an α of 0.70 is considered sufficient measure of internal consistency.[14] Internal consistency testing yielded α values of 0.806 for the 3-item autonomy subscale, 0.810 for competence, and 0.824 for relatedness, implying acceptable consistency of the psychological needs satisfaction scale. Possibly, having the same response categories across items on the subscale also contributed to the high α values. The obtained α values for the 3 psychological needs subscale were similar to values obtained in another study (α =0.84, 0.81, and 0.92, respectively)[15] even though the number of items was relatively greater. The subscale in the current study had a total of 9 items (3 each for autonomy, competence, and

relatedness) whereas in the afore-mentioned study, there were 12 autonomy items, 9 competence items, and 10 relatedness items (total of 31 items). We used fewer items on the psychological needs satisfaction subscale because our goal was to have a reasonable total number of questionnaire items that will not increase participant's response burden. The findings from this study indicates that the scores of items in the psychological needs satisfaction subscale of the *Need-2-Know* CVD risk questionnaire are consistent across items.

The intraclass correlation coefficient (ICC) for subscale items ranged from 0.22 to 0.68 across the psychological needs satisfaction and physical activity subscales. The items on the physical activity subscale were poorly to moderately consistent. This suggests that the scores of the PA items were not stable across items.

Generally, a test-retest correlation ≥0.80 is considered as good reliability, meaning that a construct with values greater than 0.80 is assumed to be consistent over time.[8] Scale used to assessing reliability coefficients in this study is 1 (perfect reliability); ≥0.90 (excellent reliability); ≥0.80 < 0.9 (good reliability); ≥0.7 < 0.8 (acceptable reliability); ≥ 0.6 < 0.7 (questionable reliability); ≥ 0.5 < 0.6 (poor reliability); < 0.5 (unacceptable reliability); 0 (no reliability).[16]

The test-retest correlation coefficients ranged from 0.037 to 1.000. The test-retest coefficients for the autonomy and relatedness scores had questionable reliability whereas that for competence scores showed acceptable reliability. Weighted kappa (κ_w) differs from the original kappa in that the former is used for assessing test-retest reliability for ordinal categorical variables whereas κ is used on nominal categorical variables. In the present study, κ_w ranged from 0.184 to 0.851 and were mostly significant.

Results from the two-way MANOVA analysis indicated a significant difference in autonomy, competence, and relatedness based on ethnicity and race as well as ethnicity and gender. Even though it was expected that the mean scores of these psychological needs will differ by ethnicity, race and gender, results showed no significant difference between scores when all 3 variables were assessed.

Conclusions and Implications for Research and Practice

Overall, the categorical variables showed poor reliability, implying that the scores of the subscales were not stable or consistent over time. Even though the items on the psychological needs satisfaction subscale had good consistency, their scores were unstable across time (i.e., they had poor reliability). The test-retest reliability of the *Need-2-Know* CVD risk questionnaire showed unacceptable to poor reliability of most items on its subscales. Its reliability can further be tested and improved by testing it in other young adult populations. The study attrition rate which was 31% could also be improved in future studies by using recruitment methods that will ensure a high return rate of respondents. The validity of the *Need-2-Know* CVD risk questionnaire can also be tested on a representative sample of underserved young adults.

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Chapter 6 - Conclusions and Recommendations for Future Research and Practice

The overall objectives of this study were to conduct a systematic review and identify existing tools for CVD risk assessment and possible gaps; and to adapt or create a new instrument, incorporating a behavioral component into it, and pilot-test it among young adults from underserved populations.

Five main non-clinical-based tools were identified from the systematic literature review – the Heart Disease Fact Questionnaire (HDFQ), the Health Beliefs Related to CVD-Perception measure (HBCVD), the Healthy Eating Opinion Survey, the Perception of Risk of Heart Disease Scale (PRHDS) and the WHO STEPwise approach to chronic disease factor surveillance (i.e., the STEPS instrument). However, these tools either assessed a SNAP risk factor (i.e., smoking, nutrition, alcohol consumption, and physical activity behaviors) individually or in addition to people's perceptions or knowledge related to CVD. None of the identified non-clinical-based risk assessment tool had incorporated all 4 SNAP risk factors in assessing CVD risk.

The next step after the systematic literature review was to develop a CVD risk assessment questionnaire since none of the identified non-clinical tools suited the purpose of this study. The development of the *Need-2-Know* CVD risk questionnaire involved three phases: focus group discussion (FGD); item development, and pilot-testing of questionnaire.

By incorporating the psychological needs satisfaction scale into the *Need-2-Know* CVD risk questionnaire, this study provided a basis for using SDT as a theoretical framework for explaining the motivational factors affecting people's engagement in CVD-related behaviors. This further adds on to the literature on the investigation of SDT-related constructs in relation to health behaviors, physical health, and psychological health.

Major strengths of this study include systematically reviewing the literature for tools or instruments that have been used in assessing CVD risk in young adults and the rigorous process used in the development of the *Need-to-Know* CVD risk assessment questionnaire, a non-clinical risk assessment tool to be used to assess CVD risk in underserved young adults. By reviewing the literature to identify and summarize existing or available questionnaires or instruments before developing a new one decreased the possibility of duplicating an already existing questionnaire. Using a *Qualtrics* panel for the pilot study improved the generalizability of study findings. With the *Qualtrics* panel sample, the panel is usually a quota sample, where participants are selected based on certain characteristics of interest to the researcher. In this study, a maximum quota of 55% respondents who self-identified as racial and ethnic minority was used. However, additional criteria such as total annual income and level of education could have been included.

Another limitation of this study was the challenges in recruiting focus group participants. As previously mentioned, to have a well-represented sample, we recruited participants from organizations that serve most of the general population of Manhattan, Kansas, particularly young adults from low-income families. Despite several follow-up calls and visits, community members expressed low interest. This may have partially resulted from the timing of recruitment, which coincided with summer holidays. Possibly, people might have already planned their summer and adding on an extra commitment might disrupt their plans. Some strategies that have been used to improve low community participation, especially in underserved communities include establishing partnerships with community representatives and organizations, soliciting help from a previously established community advisory board, sponsoring frequent, in-depth presentations to groups of potentially eligible individuals, emphasizing the benefits of the research to the community, and providing incentives and personalized recruitment materials.[1]

Recommendations for Future Research and Practice

To the best of our knowledge, the systematic review conducted as part of this study is the first to identify tools or instruments that have been used to assess CVD risk factors in the young adult population. The items on the subscales of the *Need-2-Know* CVD risk questionnaire showed acceptable consistency across items. However, the questionnaire showed unacceptable to poor reliability. That notwithstanding, the *Need-2-Know* CVD risk assessment questionnaire can be a valuable tool for assessing CVD risks among young adults in a non-clinical and public health settings. It will enhance the understanding of motivational factors influencing young adults' CVD-related behaviors to guide and improve CVD prevention strategies in this population.

Future research would involve the comparison of datasets from both first (Set 1) and second survey launches (Set 2) to determine differences in characteristics and responses of respondents. The internal consistency of the questionnaire for Set 1 will also be assessed and possibly, a split-half method of reliability performed to compare with the test-retest reliability results obtained from Set 2 used in this present study. The subscales that showed fair to poor reliability could be further tested in future studies. The validity of the *Need-2-Know* CVD risk assessment questionnaire can be tested in a representative sample of underserved young adults. This could be achieved by including income and educational level as additional criteria for obtaining the *Qualtrics* panel or possibly use an underserved panel if this feature is already available in *Qualtrics*. Future studies could also examine the influence of autonomy, competence, and relatedness on smoking, nutrition behaviors, alcohol use, and physical activity.

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Appendix A - Supplemental Materials Related to Systematic Review

Table 1. Search Strategy Used in PubMed

Cardiovascular Diseases		
1	cardiovascular disease*[tiab]	158,869
2	cardiovascular diseases[majr:noexp]	95,167
3	cardiovascular diseases[mh]	2,256,281
4	cardiovascular diseases[mh:noexp]	136,098
5	myocardial infarction[majr]	124,856
6	coronary disease[majr]	163,987
7	stroke[majr]	89,288
8	brain ischemia[majr:noexp]	37,147
9	cerebrovascular accident[tiab]	4,211
10	death, sudden, cardiac[majr]	9,124
11	heart diseases[majr:noexp]	48,891
12	cardiovascular mortality[tiab]	12,184
13	coronary[tiab]	378,233
14	artery[tiab]	487,812
15	disease[tiab]	2,867,168
16	*(#13) AND (#14 OR #15)*	*263,475*
17	stroke[tiab]	218,939
18	brain[tiab]	929,305
19	cerebrovascular[tiab]	53,207
20	cerebral[tiab]	344,308
21	brainstem[tiab]	43,444
22	*(#17) AND (#18 OR #19 OR #20 OR #21)*	*68,560*
23	intracranial hemorrhages[majr]	47,765
24	intracranial hemorrhage, traumatic[majr]	9,136
25	cerebral hemorrhages[majr]	21,291
26	*((#23 NOT #24)) OR #25*	*39,587*
27	*(#1 OR #2 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #16 OR #22 OR #26)*	*850,063*
Risk Assessment		
28	risk assessment[mh]	242,173
29	Risk Assess*[tiab]	60,378
30	Health Risk Assess*[tiab]	3,539
31	Risk Function*[tiab]	607
32	Risk Equation*[tiab]	583
33	Risk Calc*[tiab]	1,981
34	Risk Scor*[tiab]	17,789
35	Risk Predict*[tiab]	9,746
36	Risk Factor Calc*[tiab]	3
37	Risk Factor Assess*[tiab]	785
38	Risk Chart*[tiab]	223
39	Risk Engine*[tiab]	161

40	Risk Appraisal*[tiab]	652
41	Prediction Model*[tiab]	14,171
42	Risk algorithm[tiab]	233
43	Scoring* Method*[tiab]	43,976
44	Scoring Scheme*[tiab]	789
45	*(#28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44)*	*346,361*
Coronary Artery Disease Risk Models		
46	assign score*[tiab]	50
47	brhs[tiab]	26
48	British regional heart[tiab]	143
49	British national heart[tiab]	52
50	busselton[tiab]	247
51	decode study[tiab]	27
52	Dundee risk score*[tiab]	**4**
53	erica risk[tiab]	229
54	findris*[tiab]	165
55	framingham equation*[tiab]	205
56	framingham estim*[tiab]	8
57	framingham heart study algorithm[tiab]	**2**
58	Framingham algorithm[tiab]	49
59	Framingham guideline*[tiab]	607
60	Framingham risk[tiab]	2,622
61	Framingham score*[tiab]	402
62	Framingham function*[tiab]	52
63	Framingham model*[tiab]	98
64	Glostrup[tiab]	327
65	New Zealand chart*[tiab]	515
66	precard[tiab]	5
67	PROCAM[tiab]	233
68	Reynolds risk score*[tiab]	68
69	score project[tiab]	56
70	Sheffield table*[tiab]	**34**
71	shaper score*[tiab]	21
72	Systematic Coronary Risk Evaluation[tiab]	296
73	*(#46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70 OR #71 OR #72)*	*5,706*
Tools		
74	(surveys and questionnaires[majr:noexp])	*42,079*
75	patient reported outcome measures[majr:noexp]	1,630
76	health care surveys[majr:noexp]	3,808
77	survey tools[tiab]	201
78	survey instrument*[tiab]	3,760

79	community surveys[majr:noexp]	*42,079*
80	("surveys and questionnaires"[tiab])	889
81	(#74 NOT #80)	42,027
82	outcome measure*[tiab]	207,525
83	outcome assessments[tiab]	1,121
84	*(#75 OR #76 OR #77 OR #78 OR #81 OR #82 OR #83)*	*256,161*
Underserved populations		
85	vulnerable populations[majr:noexp]	4,132
86	medically underserved area*[majr:noexp]	3,189
87	disadvantaged populations[tiab]	851
88	(underserved[tiab]) AND (patients OR populations[tiab])	4,624
89	sensitive population*[tiab]	*537*
90	sensitive population group*[tiab]	17
91	medically underserved population*[tiab]	246
92	(#86 OR #91)	3,377
93	(#89 OR #90)	*537*
94	(limited) AND health resource*[mh]	1,670
95	*(#85 OR #87 OR #88 OR #92 OR #93 OR #94)*	*14,124*
Summation		
96	*(#45 AND #84 AND #73)*	*149*
97	(#27 AND #96 AND English[la] AND humans[mh] AND young adult*[mh] AND 2008:2019[dp])	5
98	(#27 AND #96 AND English[la] AND humans[mh] AND #95 AND 2008:2019[dp])	0
99	(#27 AND #96 AND English[la] AND humans[mh] AND young adult*[mh] AND #95 AND 2008:2019[dp])	0
100	*(#27 AND #96 AND English[la] AND humans[mh] OR young adult*[mh] AND #95 AND 2008:2019[dp])*	*1,126*
101	(#27 AND #96 AND English[la] AND humans[mh] AND young adult*[tiab] AND 2008:2019[dp])	1
102	*(#27 AND #96 AND English[la] AND humans[mh] OR young adult*[tiab] AND #95 AND 2008:2019[dp])*	*59*
103	*(#45 OR #84 OR #73)*	*594,736*
104	(#27 AND #103 AND English[la] AND humans[mh] AND young adult*[mh] AND 2008:2019[dp])	2,934
105	(#27 AND #103 AND English[la] AND humans[mh] AND #95 AND 2008:2019[dp])	43
106	(#27 AND #103 AND English[la] AND humans[mh] AND young adult*[mh] AND #95 AND 2008:2019[dp])	2
107	*(#27 AND #103 AND English[la] AND humans[mh] OR young adult*[mh] AND #95 AND 2008:2019[dp])*	*1,167*
108	(#27 AND #103 AND English[la] AND humans[mh] AND young adult*[tiab] AND 2008:2019[dp])	365
109	*(#27 AND #103 AND English[la] AND humans[mh] OR young adult*[tiab] AND #95 AND 2008:2019[dp])*	102
110	*((#45 AND #84)) OR #73*	*15,915*

111	(#27 AND #110 AND English[la] AND humans[mh] AND young adult*[mh] AND 2008:2019[dp])	298
112	(#27 AND #110 AND English[la] AND humans[mh] AND #95 AND 2008:2019[dp])	6
113	(#27 AND #110 AND English[la] AND humans[mh] AND young adult*[mh] AND #95 AND 2008:2019[dp])	0
114	*(#27 AND #110 AND English[la] AND humans[mh] OR young adult*[mh] AND #95 AND 2008:2019[dp])*	1,132
115	(#27 AND #110 AND English[la] AND humans[mh] AND young adult*[tiab] AND 2008:2019[dp])	33
116	*(#27 AND #110 AND English[la] AND humans[mh] OR young adult*[tiab] AND #95 AND 2008:2019[dp])*	65
Tools in young adults (SR research question 1)		
117	#97 OR #101 OR #104 OR #108 OR #111 OR #115	3,108
118	#117 AND letter[pt]	23
119	#117 AND comment[pt]	17
120	#117 AND editorial[pt]	14
121	#118 OR #119 OR #120	42
122	#117 NOT #121	**3,066 (3,110 as at 5/28/19; 3,121 as at 5/29/19)**
Tools for underserved young adults (SR research question 2)		
123	#100 OR #102 OR #105 OR #106 OR #107 OR #109 OR #112 OR #114 OR #116	1,188
124	#123 AND letter[pt]	5
125	#123 AND comment[pt]	0
126	#123 AND editorial[pt]	2
127	#124 OR #125 OR #126	7
128	#123 NOT #127	**1,181**

Appendix B - Supplementary Materials Related to Focus Groups

K-STATE Research and Extension

Department of Food, Nutrition, Dietetics and Health
207 Justin Hall
Manhattan, KS 66506-1407
785-532-5782
FAX: 785-532-1678
www.ksre.ksu.edu/humannutrition

Konza Prairie Community Health Center
2030 Tecumseh Rd
Manhattan, KS 66502
Phone: (785) 320.7134

October 14, 2019

Dear Sir/ Madam:

REQUEST FOR PARTICIPANTS FOR A RESEARCH STUDY

My name is Audrey Opoku-Acheampong, and I am a Doctoral student in the Department of Food, Nutrition, Dietetics, and Health at Kansas State University. Our research team is facilitating discussions about lifestyle behaviors related to cardiovascular disease (heart disease) risks. We are writing to request your permission to invite members or patrons of your organization to participate in our study. The results of this discussion will help us develop a survey instrument to identify cardiovascular disease risk factors in young adults. The Kansas State University Institution Review Board has approved this study (IRB #9673).

Interested persons should be between **18 and 34** years of age. The discussion will last approximately 60 to 90 minutes. Participation is voluntary. There is no cost or likely risks associated with participation. Group discussions will be audio recorded for note taking purposes. No names will ever be associated with the notes and participants may discontinue participation at any time.

Participants will receive an incentive of $30 upon completion of the session.

If you have any questions about the study, please email or contact my major professor, Dr. Tandalayo Kidd at 785-532-0154/ martan@ksu.edu, or me at 785-532-0159/ abampoe@ksu.edu.

Thank you very much.

Sincerely,

Audrey Opoku-Acheampong, MS
249 Justin Hall
Kansas State University
Manhattan, KS 66506

Figure 1. Sample Recruitment Letter to Organizations

KANSAS STATE UNIVERSITY

K-STATE Research and Extension

Want to earn $30 CASH for less than 60-90 minutes of your time?

- **Are you between 18-34 years of age?**
- **Are you willing to participate in a group discussion about lifestyle behaviors related to heart disease risk?**

K-State Research and Extension at Kansas State University is recruiting people to participate in a group discussion about lifestyle behaviors related to heart disease risk. If you are interested or would like to know more information, please contact Audrey Opoku-Acheampong at 785-532-0159 (abampoe@ksu.edu) or Dr. Tanda Kidd at 785-532-0154 (martan@ksu.edu).

Limited spots available. Call today!

The Kansas State University Institution Review Board has approved this study (IRB #9673).

Figure 2. Sample Recruitment Postcard Flyer

Focus Groups Moderation Guide – Assessing Heart Disease Risk Factors in Young Adult Populations

Introductory Questions

Let's go round the table, starting with _____. Please introduce yourself using your first name only for data analysis purposes only. None of the information you provide in this discussion will be associated or linked to you in any way.

1.
    a. When you hear "cardiovascular disease", what comes to mind?
    b. When you hear "heart disease", what comes to mind?
        i. Probe: Please tell me what can make someone develop heart disease?

Please note that hereafter, I will use "heart disease" to mean both CVD and heart disease.

Risk Factors

Now, we are going to shift our focus to smoking.

2. Please share some reasons why a person might smoke.
    a. Probe: How might smoking affect one's health?

Now, let's shift our focus to alcohol use.

3. What comes to mind when you hear about alcohol use?
    a. Probe: What do you think are some reasons some people may drink alcohol?
    b. Probe: How might drinking alcohol affect one's health?

Changing focus, let's talk about eating habits.

4. Please share how eating habits can affect a person's health.
    a. Probe: Please share your thoughts on some foods you believe will be healthful or harmful for heart health.
    b. Probe: What can prevent someone from eating healthy?
    c. Probe: What can encourage someone to eat healthy?

Now, let's talk about exercise.

5. Please share about how exercise can affect a person's health.
    a. Probe: What are some things that can prevent someone from exercising?
    b. Probe: What are some things that can encourage someone to exercise?

Prevention/Reduction

6. Do you think people should be concerned about heart disease?
    a. Probe: Please, can you explain your answer?
    b. Probe: What community resources are you aware of that addresses heart disease?
    c. Probe: What do you think is the best way to provide information on heart disease to make it better to understand these factors?

Is there anything else related to the topics we discussed today that you think I should know that I didn't ask or that you have not yet shared?

This ends our focus group discussion today. Please remember to complete the questions about your background information. Thank you for your time!

Appendix C - Supplementary Materials Relating to Questionnaire Development

Need-2-Know Heart Disease Risk Assessment Questionnaire

Informed Consent

Purpose: K-State Research and Extension at Kansas State University is inviting people to complete this online survey to learn about heart disease risk factors among young adults from underserved populations.

Procedure: This online survey will last approximately 20 minutes.

Risk: Except for your time and inconvenience, the risk to you is minimal. There may be minimal risk of data being intercepted during the completion and transmission of the online surveys. This risk will be reduced by using an encrypted transmission for online surveys. No names will ever be associated with your responses.

Benefit: When you have completed the survey, you will receive an incentive of $5 for participating. Also, participation in the study may help researchers identify ways to help communities move towards heart disease prevention. Participation is voluntary and you may discontinue participation at any time. If you leave the study for any reason, you will not be eligible for the $5.

Confidentiality: All information that you provide will be kept confidential and your privacy will be protected to the maximum extent allowable by law. The data will be stored in a secured location in the Department of Food, Nutrition, Dietetics and Health at Kansas State University. When data are presented for scientific purposes, data will be reported in summary format, and no names or other identifiable information will be used.

Rights and Complaints: If you have any questions about this project, please contact Dr. Tandalayo Kidd, 245A Justin Hall, Kansas State University, Manhattan, KS 66506, martan@ksu.edu or Audrey Opoku-Acheampong, abampoe@ksu.edu. If you have any questions about your rights as a participant in this study, you may contact Dr. Rick Scheidt, Chair, Committee on Research Involving Human Subjects, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224. This study has been approved by the Institutional Review Board of the Kansas State University (IRB# 9673)

Select a button below to indicate whether you accept or decline participation in the study.

- ☐ Yes, I accept participation
- ☐ No, I decline participation

This survey is about health behaviors related to cardiovascular disease (i.e., diseases of the heart, blood, and blood vessels) risks; the information you provide will be used to improve health education resources for young people like yourself. Please answer the questions as best as you can.

Completing the survey is voluntary; thus, you may leave a particular question blank if you are uncomfortable answering it.

The questions about personal information, such as age, income, etc. will only be used to describe the characteristics of people taking this survey. None of the information provided on this survey will be used to track you down, and responses will not be shared with any one not affiliated with the project.

Thank you.

	A. Behavioural Risk Factors (RF)	
	TOBACCO USE *The following questions ask about your tobacco use (e.g., cigarettes, cigars, or pipes)*	
1	Regarding tobacco smoking, please choose which one applies to you.	1 I have never smoked → Go to Question 6 2 I am a Previous/Ex-smoker → Go to Question 5 3 I am a current smoker 4 Prefer not to answer
2	How long have you been smoking?	2 Number of years __ 3 Number of months ___ 4 Number of weeks ___ 5 Don't know 6 Prefer not to answer
3	On average, how many of the following products do you smoke each day/week?	
	6 Manufactured cigarettes 7 Hand-rolled cigarettes 8 Pipes full of tobacco 9 Cigars 10 Other (Please specify) _____ 11 Prefer not to answer	Daily ___ Weekly ___ Daily ___ Weekly ___ Daily ___ Weekly ___ Daily ___ Weekly ___ Daily ___ Weekly ___
4	During the past 12 months, have you tried to stop smoking?	1 Yes 2 No 3 Prefer not to answer
5	How long did you smoke?	2 Number of years __ 3 Number of months ___ 4 Number of weeks ___ 5 Don't know 6 Prefer not to answer
6	Do you currently use any smokeless tobacco products [such as snuff, chewing tobacco, chew, dip]? *Smokeless tobacco products are placed in the mouth or nose.* Do not count any electronic vapor products.	1 Yes 2 No → If No, go to Question 8 3 Prefer not to answer
7	How often do you use smokeless tobacco products?	1 Yes 2 No 3 Prefer not to answer

The next 2 questions ask about electronic vapor products, such as JUUL, Vuse, MarkTen, and blu.

Electronic vapor products include e-cigarettes, vapes, vape pens, e-cigars, e-hookahs, hookah pens, and mods. [E-cigarettes look like regular cigarettes but are battery-powered and produce vapor instead of smoke.]

8	Have you ever used an electronic vapor product?	1 Yes 2 No → If No, go to Question 10
9	During the past 30 days, on how many days did you use an electronic vapor product?	1 0 days 2 1 or 2 days 3 3 to 5 days 5 6 to 9 days 4 10 to 19 days 5 20 to 29 days 6 All 30 days 7 Prefer not to answer

ALCOHOL USE

The next questions ask about the consumption of alcohol.

One standard alcoholic drink or beverage is defined as 12 fluid ounces (fl oz) of regular beer, 5 fl oz of table wine, or 1.5 fl oz shot of distilled spirits (gin, rum, tequila, vodka, whiskey, etc.).

For these questions, drinking alcohol does not include drinking a few sips of wine for religious purposes.

10	Have you consumed any alcohol within the past 12 months?	1 Yes 2 No → If No, go to Question 13 3 Prefer not to answer
11	During the past 12 months, how frequently have you had at least one standard alcoholic drink?	1 Daily 2 5-6 days per week 3 3-4 days per week 4 1-2 days per week 5 1-3 days per month 6 Less than once a month 7 Never 8 Prefer not to answer
12	Thinking about the past 7 days. How many standard drinks did you have each day?	4 Monday _____ 5 Tuesday _____ 6 Wednesday ___ 7 Thursday _____ 8 Friday _____ 9 Saturday _____ 10 Sunday _____ 11 Prefer not to answer
13	Have you stopped consuming alcohol due to health reasons, such as a negatively impacting your health	1 Yes 2 No

	or because of your doctor or other health worker's advice?	3 Prefer not to answer
DIET *The following questions ask about the foods you ate or drank during the past month, that is, the past 30 days. Think about all the meals and snacks you had from the time you got up until you went to bed. When answering, please include meals and snacks you ate at home, at school or work, at restaurants, and anywhere else.*		
14	During the past month, how often did you eat cooked or raw dark-green, red, and orange vegetables, such as green leafy or lettuce salad, spinach, kale, tomatoes, red peppers, carrots, and sweet potatoes?	1 Never 2 1 time last month 3 2-3 times last month 4 1 time per week 5 2 times per week 6 3-4 times per week 7 5-6 times per week 8 1 time per day 9 2 or more times per day 10 Prefer not to answer
15	During the past month, how often did you eat cooked legumes (beans and peas) such as refried beans, baked beans, beans in soup, pork and beans or any other type of cooked dried beans? Do not include green beans or green peas.	1 Never 2 1 time last month 3 2-3 times last month 4 1 time per week 5 2 times per week 6 3-4 times per week 7 5-6 times per week 8 1 time per day 9 2 or more times per day 10 Prefer not to answer
16	During the past month, how often did you eat starchy vegetables such as white potatoes, corn, green beans, plantains, and cassava?	1 Never 2 1 time last month 3 2-3 times last month 4 1 time per week 5 2 times per week 6 3-4 times per week 7 5-6 times per week 8 1 time per day 9 2 or more times per day 10 Prefer not to answer
17	During the past month, how often did you eat other vegetables (not including leafy green salads, potatoes, or cooked dried beans)?	1 Never 2 1 time last month 3 2-3 times last month 4 1 time per week 5 2 times per week 6 3-4 times per week 7 5-6 times per week 8 1 time per day

		9 2 or more times per day 10 Prefer not to answer
18	During the past month, how often did you eat fruit (include fresh, frozen, canned, dried or 100% fruit juices)? Do not include fruit-flavored drinks.	1 Never 2 1 time last month 3 2-3 times last month 4 1 time per week 5 2 times per week 6 3-4 times per week 7 5-6 times per week 8 1 time per day 9 2 or more times per day 10 Prefer not to answer
19	During the past month, how often did you eat whole-grain foods such as whole-wheat bread, whole-grain cereals and crackers, oatmeal, quinoa, popcorn, and brown rice? Do not include white bread and white rice.	1 Never 2 1 time last month 3 2-3 times last month 4 1 time per week 5 2 times per week 6 3-4 times per week 7 5-6 times per week 8 1 time per day 9 2 or more times per day 10 Prefer not to answer
20	During the past month, what kind of milk did you usually drink?	1 Whole or regular milk 2 2% fat or reduced-fat milk 3 1%, ½%, or low-fat milk 4 Fat-free, skim or nonfat milk 5 Soy milk 6 Other kind of milk. *Please specify* _____ 7 Prefer not to answer
21	During the past month, how often did you have dairy foods? Include milk, cheese, and cheese products.	1 Never 2 1 time last month 3 2-3 times last month 4 1 time per week 5 2 times per week 6 3-4 times per week 7 5-6 times per week 8 1 time per day 9 2-3 times per day 10 4-5 times per day 11 6 or more times per day 12 Prefer not to answer
22	During the past month, how often did you eat red meat, such as beef, pork, ham, or sausage? Do not include chicken, turkey, or seafood. Include red meat you had in sandwiches, lasagna, stew,	1 Never 2 1 time last month 3 2-3 times last month 4 1 time per week

	and other mixtures. *Red meats may also include veal, lamb, and any lunch meats made with these meats.*	5 2 times per week 6 3-4 times per week 7 5-6 times per week 8 1 time per day 9 2 or more times per day 10 Prefer not to answer
23	During the past month, how often did you drink sugar-sweetened beverages (i.e., drinks to which sugar has been added) such as regular soda or pop, sweetened coffee and tea, sweetened fruit drinks, sports or energy drinks, and flavored water? Examples: *Arizona* Iced Tea, Frappuccino, *Kool-Aid*, lemonade, *Hi-C*, cranberry drink, *Gatorade*, *Red Bull* or Vitamin Water. Do not include diet soda, tea or drinks or artificially sweetened coffee or drinks.	1 Never 2 1 time last month 3 2-3 times last month 4 1 time per week 5 2 times per week 6 3-4 times per week 7 5-6 times per week 8 1 time per day 9 2-3 times per day 10 4-5 times per day 11 6 or more times per day 12 Prefer not to answer
24	During the past month, how often did you eat sugary snacks and desserts, including candies, doughnuts, sweet rolls, Danish, muffins, pan dulce, pop-tarts, cookies, cake, pie, brownies, ice cream or other frozen desserts? Do not include sugar-free products.	1 Never 2 1 time last month 3 2-3 times last month 4 1 time per week 5 2 times per week 6 3-4 times per week 7 5-6 times per week 8 1 time per day 9 2 or more times per day 10 Prefer not to answer
Dietary salt *Dietary salt includes ordinary table salt, unrefined salt such as sea salt, iodized salt, salty stock cubes and powders, and salty sauces such as soy sauce or fish sauce.* *The following questions ask about your salt/sodium intake.* *Please answer the questions even if you consider yourself to eat a diet low in salt/sodium.*		
25	How often do you add salt or a salty sauce such as soy sauce to your food right before you eat it or as you are eating it?	1 Always 2 Often 3 Sometimes 4 Rarely 5 Never 6 Don't know 7 Prefer not to answer
26	How often is salt, salty seasoning or a salty sauce added in cooking or preparing foods in your household?	1 Always 2 Often 3 Sometimes 4 Rarely 5 Never

		6 Don't know 7 Prefer not to answer
27	During the past month, how often did you eat any processed meat, such as bacon, lunch meats, or hot dogs? Include processed meats you had in sandwiches, soups, pizza, casseroles, and other mixtures.	1 Always 2 Often 3 Sometimes 4 Rarely 5 Never 6 Don't know 7 Prefer not to answer
28	How much salt or salty sauce do you think you consume?	1 Far too much 2 Too much 3 Just the right amount 4 Too little 5 Far too little 6 Don't know 7 Prefer not to answer

PHYSICAL ACTIVITY

The next 7 questions ask about your physical activity participation in a typical week. We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. Please answer these questions even if you do not consider yourself to be a physically active person. Please think of the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise, or sport.

Think about all the vigorous activities that you did in the last 7 days. Vigorous physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think <u>only</u> about those physical activities that you did for at least 10 minutes at a time.

29	During the last 7 days, on how many days did you do vigorous physical activities like heavy lifting, digging, aerobics, or fast bicycling?	2 _____days per week 3 No vigorous physical activities → Go to question 31 4 Prefer not to answer
30	How much time did you usually spend doing vigorous physical activities on one of those days?	1 _____hours per day 2 _____minutes per day 3 Don't know/Not sure 4 Prefer not to answer

Think about all the moderate activities that you did in the last 7 days. Moderate activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal. Think only about those physical activities that you did for at least 10 minutes at a time.

31	During the last 7 days, on how many days did you do moderate physical activities like carrying light loads,	1 _____days per week 2 No moderate physical activities → Go to question 33 3 Prefer not to answer

	bicycling at a regular pace, or doubles tennis? Do not include walking.	
32	How much time did you usually spend doing moderate physical activities on one of those days?	1 _____hours per day 2 _____minutes per day 3 Don't know/Not sure 4 Prefer not to answer
Think about the time you spent walking in the last 7 days. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.		
33	During the last 7 days, on how many days did you walk for at least 10 minutes at a time?	1 _____days per week 2 No walking → Go to question 35 3 Prefer not to answer
34	How much time did you usually spend walking on one of those days?	1 _____hours per day 2 _____minutes per day 3 Don't know/Not sure 4 Prefer not to answer
The last question is about the time you spent sitting on weekdays during the last 7 days. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.		
35	During the last 7 days, how much time did you spend sitting on a weekday?	1 _____hours per day 2 _____minutes per day 3 Don't know/Not sure 4 Prefer not to answer

B. Psychological Needs Satisfaction – *Concerning needs for competence, autonomy, and relatedness*

Please read each of the following items carefully, thinking about how it relates to your life, and then indicate how true it is for you. Use the following 5-point scale to respond:

1	*2*	*3*	*4*	*5*
Not at all				*Very much*

In my life I feel …

1 That my choices are based on my true interests and values.
2 Free to do things my own way.
3 That my choices express my "true self".

4 That I successfully complete difficult tasks and projects.
5 That I take on and master hard challenges.
6 Very capable in what I do.
7 A sense of contact with people who care for me, and whom I care for.
8 Close and connected with other people who ae important to me.
9 A strong sense of intimacy with the people I spend time with.

C. Personal medical history

Has a doctor or anyone ever told you that you have/had? _____

1. Heart disease?	1. Yes	2. No	3. Prefer not to answer
2. Heart attack/stroke?	1. Yes	2. No	3. Prefer not to answer
3. High blood pressure?	1. Yes	2. No	3. Prefer not to answer
4. Type II diabetes?	1. Yes	2. No	3. Prefer not to answer
5. Cancer	1. Yes	2. No	3. Prefer not to answer

D. Type of Health Insurance. ***Select all that apply***

1. None 2. Medicare or Medicaid 3. Private 4. Other 5. Unsure
6. Prefer not to answer

E. Demographics

1. What is your age (in years)? _____
2. What is your gender? 1. Male 2. Female 3. Prefer not to answer
3. Are you Hispanic or Latino?
    a. Yes
    b. No
    c. I don't know/Not sure
    d. Prefer not to answer
4. Which one or more of the following would you say is your race?
    a. American Indian or Alaskan Native
    b. Asian
    c. Black or African American
    d. Native Hawaiian or Other Pacific Islander

e. White

f. Other (Please specify)_____

g. Prefer not to answer

5. What is your **highest level of education**?

   a. Less than high school

   b. High school degree or equivalent (e.g., GED)

   c. Some college but no degree

   d. Associate degree/Technical school graduate

   e. Bachelor's degree

   f. Graduate degree

   g. Other (Please specify) _____

   h. Prefer not to answer

6. Which of the following best describes your employment status?

   a. Employed, full-time

   b. Employed, part-time

   c. Unemployed, looking for work

   d. Unemployed, NOT looking for work

   e. Homemaker

   f. Disabled, not able to work

   g. Student

   h. Other. Please specify _____

   i. Prefer not to answer

7. What is your annual household income from all sources?

   a. $0 to $9,999

   b. $10,000 to $24,999

   c. $25,000 to $49,999

   d. $50,000 and above

   e. Prefer not to answer

8. At what type of health care place do you usually receive your medical care? (*Select all that apply*)
    a. None
    b. Hospital
    c. Clinic
    d. Health Department
    e. Hospital Emergency Room
    f. Other (Please specify) _____
    g. Prefer not to answer
9. Where do you obtain health information from? (*Select all that apply*)
    a. Family doctor or other medical professional
    b. Family or friends
    c. Mass media – television, radio, public library
    d. Internet
    e. Print media
    f. Churches or community groups
    g. Other (Please specify)_____
    h. No information sources/non-seeker
    i. Prefer not to answer

This is the end of the survey. Thank you for your time and responses!

If you have any questions about your rights as a participant in this study, you may contact Dr. Rick Scheidt, Chair, Committee on Research Involving Human Subjects, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224. This study has been approved by the Institutional Review Board of the Kansas State University (IRB# 9673)

Select a button below to indicate whether you accept or decline participation in the study.

- ◯ Yes, I accept participation
- ◯ No, I decline participation

Q1. Are you Hispanic or Latino?

- ◯ Yes
- ◯ No
- ◯ I don't know/Not sure
- ◯ Prefer not to answer

Q2. Which one or more of the following would you say is your race?

- ◯ American Indian or Alaskan Native
- ◯ Asian
- ◯ Black or African American
- ◯ Native Hawaiian or Other Pacific Islander
- ◯ White
- ◯ _____ Other (Please specify)
- ◯ Prefer not to answer

Q3. What is your age (in years)?

Figure 1. Sample Qualtrics Version of Questionnaire