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How to Offer Culturally Relevant Type 2 Diabetes Screening: Lessons Learned from the South Asian Diabetes Prevention Program

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ABSTRACT

The literature on diabetes mellitus in the South Asian population clearly states the high-risk status of this group, yet there is a lack of effective models of culturally relevant, community-based screening and education programs for such a group. The South Asian Diabetes Prevention Program (SADPP) was developed to enhance equitable access to diabetes prevention resources for the South Asian communities in Toronto by offering language-specific and culturally relevant services. The SADPP model works through 3 participant education sessions plus an additional attachment and enrolment component. The screening tool that SADPP uses to provide participants with their individual risk score at the first education session is derived from the multiculturally validated Canadian Diabetes Risk Assessment Questionnaire (CANRISK), which has been modified to reflect the distinctive characteristics of the South Asian population. After analyzing the risk scores, 32% of participants were at increased risk, 40% were at high risk, 21% were at very high risk and only 7% were found to be at low risk of diabetes development. Evaluations of the program conducted in 2010 and 2013 revealed that the program is achieving its objectives and that participants increase their knowledge and self-efficacy related to diabetes prevention after program participation. Participants reported that the presentation from the nurse and dietitian, the question-and-answer time, the healthy eating demonstration, the multiple languages of delivery and the convenient location were especially beneficial. Those working in the field are encouraged to adapt this model and to contribute to the development of culturally relevant, community-driven diabetes prevention programs.

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R É S U M É

La littérature sur le diabète sucré de la population de l'Asie du Sud indique clairement le risque élevé de ce groupe, mais il manque de modèles efficaces de dépistage communautaire et de programmes d'éducation qui tiennent compte de la culture d'un tel groupe. Le SADPP (South Asian Diabetes Prevention Program) était mis sur pied pour accroître l'accès équitable aux ressources en matière de prévention du diabète des communautés sud-asiatiques de Toronto en offrant des services qui tiennent compte de leur langue et de leur culture. Le modèle du SADPP intègre 3 séances d'éducation des participants ainsi qu'une composante supplémentaire d'engagement et d'adhésion. L'outil de dépistage que le SADPP utilise pour fournir aux participants leur score de risque individuel à la première séance d'éducation est tiré du Questionnaire canadien sur le risque du diabète CANRISK, qui a été modifié pour refléter les caractéristiques de la population sud-asiatique. Après l'analyse des scores de risque, 32 % des participants étaient exposés à un risque accru, 40 % étaient exposés à un risque élevé, 21 % étaient exposés à un risque très élevé et seulement 7 % montraient un faible risque de développement du diabète. Les évaluations du programme menées en 2010 et 2013 révélaient que le programme avait atteint ses objectifs et que les participants avaient amélioré leurs connaissances et la connaissance de leurs propres capacités liée à la prévention du diabète après la participation au programme. Les participants rapportaient que la présentation de l'infirmière et de la diététiste, le temps alloué aux questions et aux réponses, la démonstration d'une saine alimentation, les diverses langues de prestations et

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l'emplacement pratique étaient particulièrement utiles. Ceux travaillant dans le domaine sont encouragés à adapter ce modèle et à contribuer à l'élaboration de programmes communautaires de prévention du diabète qui tiennent compte de la culture.

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Introduction

The literature on diabetes mellitus in the South Asian (SA) population clearly states the high-risk status of this group (1,2). Research on diabetes prevalence in Ontario shows that almost 12% of the immigrated SA population living in Ontario is living with type 2 diabetes, compared with 5.2% of the general population (2). Additionally, it is well known that both prediabetes and diabetes disproportionately affect socially and economically disadvantaged groups, including recent immigrants (3). The need for culturally relevant programming is evident, and that is reflected in both research discourse and professional practice (4,5).

Emerging literature also dictates the vital importance of prevention, and highlights screening programs as a key component of prevention efforts (6,7). Although there is no evidence that screening efforts lead to improved cardiovascular outcomes (8), screening among high-risk populations has proven to be an effective practice for the early detection of diabetes (9–11), especially 2-step screening (12). The most accurate screening modalities are invasive and time consuming, and not likely suitable for community level, population-based screening (13). Thus, screening people who are known to be at risk for type 2 diabetes through a simple method that combines risk factor assessment with simple blood glucose testing may be an effective public health strategy. This approach has been evaluated in other populations with encouraging results (14–17), but there is a lack of evidence on the efficacy of screening approaches in the SA population (8).

Unfortunately, there is a paucity of evidence on effective models of culturally relevant, community-based screening and education programs, especially for the SA population in Ontario. A diabetes screening and awareness program was developed in Alberta for the Indo-Asian population (18). Research from this program has further emphasized the need for culturally relevant community-based diabetes prevention strategies for high-risk populations in this country (5,18). Here, we share evidence for and models of practice from the South Asian Diabetes Prevention Program (SADPP) for other groups working to develop culturally relevant diabetes programs in the field.

Program description

The SADPP model was developed by Flemingdon Health Centre in Toronto and is funded by the Toronto Centre Local Health Integration Network. The overall goal of the program is to enhance equitable access to diabetes prevention resources for the SA communities in Toronto by offering language-specific and culturally relevant services. The SADPP model involves screening participants for diabetes and prediabetes, providing education sessions on preventing diabetes and on healthy living, and making referrals that are responsive to participants' needs. A logic model describing the program activities, objectives, outputs and outcomes can be seen in the [Figure 1](#).

Typical barriers to diabetes prevention that have been identified and targeted by SADPP include transportation, language, cost and health literacy. The SADPP model addresses these barriers by setting up mobile clinics that provide free services in the community in languages that participants are comfortable speaking, using culturally relevant practices. Screening sessions and materials are

offered in SA languages, and suggestions for lifestyle modifications are intended to reflect the daily lives and distinct diets and cultures of participants. The program team is able to achieve this level of cultural competence through the support of SA staff members who speak the languages. Screenings are conducted at locations where the target population meets regularly (for example, places of worship, settlement and newcomer centres, public schools, and so forth).

A multidisciplinary team consisting of a registered nurse, a registered dietitian, community outreach workers, a database entry assistant and a program coordinator delivers the activities of SADPP. The SADPP community outreach workers connect with unique groups of SAs by contacting an organization and developing a relationship with that group. After determining interest and coordinating schedules, the SADPP team arranges an early detection clinic (EDC) for the organization's members and the surrounding community. Efforts are made in particular to reach out to persons and communities who are marginalized, socially and economically disadvantaged, and do not traditionally access health promotion services particularly owing to resettlement. SADPP's outreach strategy consists of person-to-person engagement in the community with prospective groups; conducting information sessions to recruit participants for the program; and collaborating with community leaders, volunteers and key stakeholders to assist with program attendance, session logistics and interpretation. The team will continue to work with each new group until participants have been through all 3 encounters.

The SADPP model works through 3 participant encounters, plus an additional attachment and enrolment component. The first encounter is a 3-hour EDC, a first-step screening to identify SA program participants who are at risk of having diabetes. Before the screening process begins, staff provide an interactive education and awareness session about diabetes and prediabetes risk factors. Participants from SA communities are first screened at the EDC using an evidence-based tool tailored to the population, which groups participants into categories of low risk, increased risk, high risk, very high risk, and living with diabetes. Contrary to the Canadian Diabetes Risk Assessment Questionnaire (CANRISK) tool, which is self-administered (18,19), the SADPP screening tool is tailored to the SA population based on risk criteria for this specific population and is administered by the SADPP team at the 3 distinct stations of the EDC.

Station 1, risk assessment

When participants begin the clinic, they meet with an outreach worker to initiate the risk assessment of the screening process.

Station 2, physical activity and anthropometrics

Next, participants move on to see the dietitian for the physical activity, body mass index (BMI) and waist circumference assessment.

Station 3, cardiovascular risk and capillary blood glucose testing

Finally, participants see the nurse for cardiovascular risk factors, blood glucose testing, the risk score calculation and subsequent referral. The blood glucose testing in this station is done for educational purposes to give clients an understanding of what a blood glucose test is and how it is obtained, and to demystify the blood glucose testing process that might otherwise be intimidating in a clinical environment. The results are not used in risk score



Program Logic Model

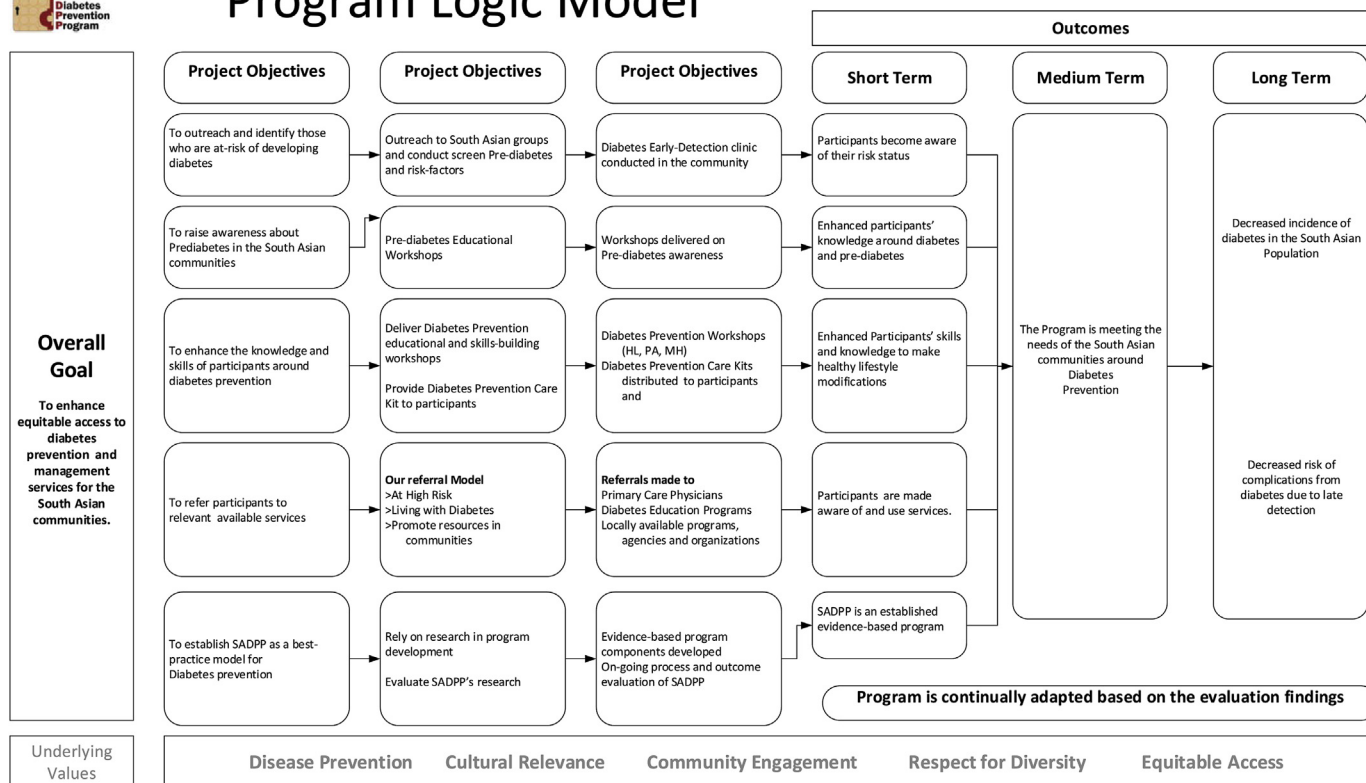


Figure 1. South Asian Diabetes Prevention Program (SADPP) program logic model.

calculations as they are not considered to be well-suited for reliable risk scoring. Furthermore, the test helps to identify those participants who would gain from future follow up and second-step screening. For second-step screening, patients who are identified at the EDC as having high glucose values are referred back to their primary care provider (PCP), or connected to a new PCP if they are unattached, for further examination and diagnosis. The registered nurse helps participants by completing a referral form, which is sent directly to the PCP for second-step screening, where the PCP may perform further testing (for example, an oral glucose tolerance test). Patients who are identified as living with diabetes are connected with diabetes education programs (DEP).

The second encounter is the diabetes prevention workshop (DPW), which is an interactive workshop focusing on the 3 pillars of diabetes prevention, which are healthful eating, physical activity and mental health. These 3 areas correspond to lifestyle issues that increase diabetes risk and impact SA persons particularly as a result of resettlement in Canada (20–22). This session includes a healthful salad preparation demonstration and practical advice for lifestyle modification tailored to SA communities. Although participants leave the first encounter with an enhanced understanding of their own individual risk factors, they leave the second encounter with enhanced knowledge and skills around making evidence-based modifications to their lifestyles.

The third encounter includes a workshop for only the highest risk participants, roughly 1 month after the second encounter, that revisits important prediabetes awareness and prevention concepts from the EDC and the DPW. At this session, participants are asked about lifestyle changes they have been attempting since attending the program, and the clinicians help brainstorm tailored and practical solutions that respond to their personal barriers.

Participants are then further referred to healthcare providers, such as social workers and dietitians, as needed.

In response to requests from participants, SADPP developed a diabetes prevention care kit for SA participants. The kits contain an evidence-based handbook and DVD (in English/Urdu and English/Tamil) that reflect the content of the EDC and DPW (diabetes awareness, healthful eating, physical activity and mental health), a healthy plate tool, a pedometer, measuring spoons and a waist-measuring tape. Currently, these kits are given out to highest risk participants at the SADPP third encounter sessions to reinforce key diabetes prevention messages delivered in the program.

The fourth encounter, the attachment and enrolment component, was designed in 2012 to better connect participants who are unattached to either PCPs or DEPs. This component involves a SADPP team member following up by telephone with such participants to confirm that they were able to connect with the PCP or DEP to which they were referred and troubleshooting accordingly. This follow up also allows SADPP to document enablers and barriers to accessing and remaining attached to these services.

Screening tool description

The screening tool that SADPP uses at the EDC to provide participants with their individual risk score is derived from the multiculturally validated CANRISK tool (19), but has been modified to reflect the distinctive characteristics of the SA population. (Contact the authors for access to the SADPP risk assessment questionnaire.) The tool is administered by the team to eliminate challenges related to health literacy and to improve the completion rate.

The SADPP risk assessment questionnaire includes sections on country of origin, age, family history, previously elevated blood

sugar, physical activity, BMI, waist circumference, cholesterol, cardiovascular disease and blood glucose measurements. South Asians have a higher proportion of body fat than other ethnic groups and, therefore, the World Health Organization has suggested lower cutoff points for BMI and waist circumference in Asian populations (23). These unique cutoffs are reflected in the modified screening tool. The physical activity assessment was also modified from the CANRISK questionnaire to better reflect current guidelines that include frequency, intensity, duration and type of physical activity (21,24). The mother and father ethnicity question was changed because for SA participants it is unnecessary to ask for the race of both the mother and the father (if either one is SA, it will produce the same risk score). The question on educational attainment was removed as participants were uncomfortable sharing this information in a public setting. Finally, the CANRISK tool includes a question on fruit and vegetable consumption that was not included in the SADDP tool because it was considered to be too subjective, and the reliability of the self-report information was thought to be low.

Additionally, after risk scoring, a simple blood test using a capillary blood glucose monitor is performed to enhance awareness around abnormal glycemic values. Participants with high blood glucose values are referred to their PCP for second-step screening. Each risk factor is assigned a score based on a scoring system modified from the CANRISK questionnaire. The screening tool concludes with the summation of individual risk factors, and participants leave the EDC with a heightened awareness of their own personal risk status. Although the risk categories are considered sufficiently close to the CANRISK categories to maintain the same risk progression, the exact predictive value of the tool is not yet known and will be further tested through a systematic validation process. Additionally, the risk scoring tool is currently utilized for the needs of the program as a way to target and re-engage the most at-risk participants for the third encounter.

Evidence for the program model

The SADPP program continually responds to emerging program evidence and attempts to make changes to the program to improve iteratively. The program was developed in 2008 after an initial needs assessment in the community. Results from 2 program evaluations conducted from 2009 to 2010 and 2012 to 2013 are briefly offered below.

All clients provided informed consent and this study was reviewed by the University of Toronto Research Ethics Board. Emerging evidence for this program model comes from focus groups, pre and post questionnaires, and follow-up calls conducted with past participants. A total of 4 focus groups were done, with participants who had attended at least 2 SADPP sessions in 2010. Self-administered questionnaires were given to participants who attended a SADPP screening or workshop in January and February 2013. That generated 35 matching pre-test and post-test responses that were analyzed using SPSS version 19.0 software (SPSS, Chicago, IL). Follow-up calls were done with 35 participants between 1 and 6 months after participants finished the program. Demographic data come from the SADPP database of 685 participants.

Analysis of 2013 data reveals that the top 5 countries of origin for participants are India, Sri Lanka, Pakistan, Bangladesh and Afghanistan. SADPP also serves persons who speak many different SA languages including, in order of prevalence, Urdu, Tamil, Hindi, Gujarati, Bengali, Dari and Punjabi. The average age of participants was 51 years, with 35% male and 65% female participants. The average BMI of the participants was 27.4 (SD \pm 4.4), much higher than the World Health Organization cutoff of 23 for an increased risk of chronic diseases (23). After analyzing the risk scores for the 491 SA participants who were assessed using the risk scoring

matrix, 32% were found to be at increased risk, 40% were at high risk and 21% were at very high risk of developing diabetes. Only 7% were found to be at low risk.

Differences were evident in participants' knowledge, attitudes and intention to change before and after SADPP participation. Participants reported knowing much more about risk factors for the development of diabetes when asked the same question before and after SADPP participation ($p < 0.001$). Increases in self-efficacy related to reducing diabetes risk were seen before and after participation with a jump in responses from 51% to 70% of participants agreeing with the statement, "I am confident I can reduce my personal risk of diabetes" ($p = 0.037$).

Follow-up calls done with participants indicated that many had made changes to their lifestyle since their last interaction with SADPP. A total of 86% of these participants reported making changes to their diet, including examples of reducing total carbohydrate, sugar, fat and sodium intake, and increasing fibre and vegetable consumption. An identical proportion (86%) of participants reported some increase to their activity levels since SADPP participation by more walking, yoga, joining an exercise facility, climbing stairs and cycling. Follow-up data revealed that participants struggled after the program with maintaining a personal physical activity plan and understanding the connection between diabetes and mental health. Participants identified wanting more support to make lifestyle changes in these areas.

Participants in all focus groups appreciated how informative the sessions were. They also highlighted the way the program raised their awareness and described the information provided as alarming and critical in highlighting the seriousness of the disease. These participants reported that the presentation from the dietitian and nurse, the question-and-answer time and the healthful eating demonstration were especially beneficial. Additionally, participants noted added comfort due to the multiple languages of delivery and the convenient location. Participants recognized several persistent barriers to change, including taste or food preference, cultural cooking, transportation, bad weather, lack of time, family responsibilities, habit, age, the cost of healthful food, financial stress and discomfort with conventional nutrition and exercise programs.

Lessons learned

Lessons learned throughout the SADPP implementation and evaluation process for those looking to implement a similar program include the following. The multidisciplinary team model allows for the contribution of expertise from distinct professions and strengthens the overall program. Keeping open lines of communications with the funder is necessary, especially for sharing successes, gaps and opportunities. Nurturing a team culture that is open and innovative gives staff permission to lead and creates a balance of teamwork and autonomy. Investing time in outreach planning and strategy allows effective reach of the intended target population and more effective program delivery overall. Building and nurturing relationships with all partners (clinical and community) leads to increased uptake and effectiveness of the program. Using project management principles as the program is operationalized is helpful in maintaining organization and maximizing learning. Finally, playing a strong advocacy role in highlighting system gaps and resource gaps in culturally relevant and language-specific programs and resources will help to ensure sustainable resources are funded and developed.

Conclusions and Future Directions

Overall, SADPP is an example of an innovative model that has shown success in reaching many of its objectives. Since the inception of the program in 2009, SADPP has screened >3200 SAs

in the Toronto area, and this diabetes prevention program model has been scaled up to other sites and different cultural groups. The program has been able to reach a high-risk population group, many of whom have been negatively affected by the resettlement process, and has been able to increase awareness of diabetes risk factors in this population. The impact of the program is clear from the changes seen in program participants. SADPP has developed an evidence-based screening tool, specifically designed for the SA population and will pursue systematic validation of this tool for further use. Currently, long-term follow up with participants is out of scope for this program, based on funding restrictions and program parameters determined by the funder. However, longer term follow-up beyond the third encounter, including re-assessment with this population, is necessary to determine development of diabetes and the preventative benefit of the program. This is a direction that SADPP will explore further, in consultation with the funder in the future.

The SADPP model will continue to focus on screening underserved and younger populations who are at risk of developing diabetes. Those working in the field are encouraged to use similar models as they design programs that are responsive to the many diverse cultural communities across Canada and to contribute to the evidence base of how to develop culturally relevant, community-driven diabetes prevention programs.

Author Disclosures

No authors have a conflict of interest to report.

Author Contributions

All authors contributed substantially to conception and design, or acquisition of data, or analysis and interpretation of data, and drafted the article or revised it critically for important intellectual content and gave final approval of the version to be published.

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