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Chronic Disease Health Literacy and Barriers and Facilitators to
Type 2 Diabetes and Hypertension Self-Management
Amongst Older Women in a South African Township

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From Community Health Workers to Community Health Coaches:
An Intervention to Reduce Sedentary Behavior to Address Obesity-Related
Chronic Disease Amongst Older Women in a South African Township

By
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B.A., University of California, Davis, 2010

Thesis

Submitted in partial fulfillment of the requirements for the
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This thesis by ***Kaitlin Gregg Goodman*** is accepted in its present form
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Prior to enrolling at Brown, Kaitlin worked at a community development nonprofit, supporting the organization's health and education programming, and developed and managed a social wellness program for employer groups at a health startup. Throughout her professional career, she has also trained as an elite runner, qualifying for the US Olympic Trials in the 5,000 meters, 10,000 meters, and marathon.

Kaitlin's interest in public health stems from her athletic background – she has long been passionate about physical activity promotion. After deferring her enrollment at Brown University to compete at the Olympic Trials, Kaitlin began her Masters in Public Health in the fall of 2016. At Brown, where she was a Global Health Scholar and recipient of the Frameworks in Global Health Award, she focused her research on obesity-related chronic disease in low- and middle-income countries. She completed an internship at the Rhode Island Department of Health, evaluating diabetes prevention programs, and she also led health promotion efforts amongst graduate students as one of two Graduate Community Fellows for Health & Wellness.

Following graduation, she plans to continue her work in physical activity promotion and chronic disease prevention amongst under-resourced communities in the US and abroad. She will also compete in the 2020 Olympic Trials in the marathon, vying for a spot on the US Olympic Team.

PREFACE AND ACKNOWLEDGMENTS

Research for this masters thesis was conducted in the township of Khayelitsha, outside of Cape Town, South Africa, in the summer of 2017. The thesis consists of two papers: one, a paper presenting the qualitative findings on health literacy and barriers and facilitators to diabetes and hypertension management amongst older women in low-resource settings; and two, an intervention proposal, rooted in theory and based on key themes that emerged from the qualitative work.

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Chronic Disease Health Literacy and Barriers and Facilitators to Type 2 Diabetes and Hypertension Self-Management Amongst Older Women in a South African Township

BACKGROUND

Chronic non-communicable diseases (NCDs) are traditionally considered problems of wealthy nations; however, today 80% of chronic disease-related deaths occur in low- and middle-income countries (LMICs)¹. The NCD burden is falling increasingly on less developed countries, many of whom face the dual burden of both infectious diseases, like HIV and TB, and NCDs. In many cases, resource-limited LMICs do not yet have the health care infrastructure to adequately address NCDs.²

Two common NCDs, Type 2 diabetes and hypertension, both have well-established links to obesity and high body mass index (BMI).³ Obesity rates in LMICs are rising: as these countries go through the nutrition transition, consuming higher-calorie diets and becoming increasingly sedentary, obesity-related disability-adjusted life years have risen, from near 1,100 per 100,000 in 1990 to over 1,600 per 100,000 in 2015.⁴ In 2013, 2 billion people were overweight or obese, with over 60% obese individuals living in LMICs.⁴ Globally and in LMICs, women face a higher burden of overweight and obesity; in developing countries in 2013, the prevalence of overweight and obesity was 32% among women, compared to 28% among men, following a trend of a higher burden amongst women that has persisted since 1980.⁶

This trend is even more pronounced in South Africa, which has the highest prevalence of obesity in all of sub-Saharan Africa.⁵ In South Africa, 41% of women are obese and nearly 70% are overweight, compared to 21% of men who are obese and nearly 40% overweight.^{7,8} Obesity rates are influenced by social determinants of health, including low socioeconomic status, built and physical environments not conducive to physical activity or proper nutrition, and lack of education that contributes to low health literacy. Together, these factors interact and have a compounding effect, resulting in the high prevalence of overweight and obesity and worse health outcomes in populations most affected by poverty and other structural factors. As obesity rates rise, so too does the chronic disease burden: between 1999 and 2006, South Africa saw increases in premature adult deaths due to hypertensive heart disease (20% increase) and diabetes (38% increase).⁶ Meanwhile, high BMI, high fasting blood glucose, and dietary risks were three of the top six risk factors in 2016 that contributed the most to death and disability in the country.⁷

Diabetes is a significant source of morbidity in South Africa: it accounted for the second-most causes of death in 2015, behind only tuberculosis (TB) and up from being the fifth-leading cause of death in 2013.⁸ An estimated 2 million South Africans suffer from diabetes, although this is likely an underestimation of the true burden, as not all cases are diagnosed.⁵ Meanwhile, nearly 40% of the population over age 15 have blood pressure levels in the prehypertensive or hypertensive ranges.⁹

Just as women in South Africa face a greater burden with obesity, they similarly face a higher burden of diabetes and hypertension. Diabetes was the leading underlying

cause of death for women in South Africa, accounting for 7.1% of all deaths, compared to 4.0% of male deaths.⁸ Hypertension accounted 5.6% of female deaths, whereas 3.0% for males.⁸ Older women are even more at risk: diabetes was the number one underlying cause of death amongst females ages 45-64 in 2015, and together with hypertensive disease, cerebrovascular disease, and other forms of heart disease, accounted for over 25% of all causes of death.⁸ Women living in low-resource communities in South Africa are especially at risk, as the distribution of chronic illness places the heaviest burden on poor communities in urban areas.^{10,11} Obesity-related chronic illness disproportionately affects urban poor blacks, with the greatest concentration of diabetes cases in South Africa being found amongst groups of low socio-economic status living in urban townships.^{6,12,13}

Health disparities within South Africa's most vulnerable populations increase their risk of developing diseases like diabetes and hypertension; this heightened risk is due to their exposure to a variety of threats to health, specifically social determinants of health. Additionally, the intersection of gender, age, race, and poverty creates compounding risk. A number of frameworks help elucidate the interconnectedness between various social and structural determinants of health. Applying Fitzpatrick and McGory's synthetic model of the role of place on health, one can draw connections between neighborhood disadvantage, such as a high concentration of poverty, and personal disadvantage, such as unemployment, while also connecting neighborhood disadvantage to limited neighborhood resources, such as the absence of grocery stores and safe places to physically recreate.¹⁴ These factors jointly contribute to specific

health beliefs and lifestyles, which can lead to reduced physical activity and poor nutrition and, in turn, poorer health outcomes. Another useful framework to understand the context of the South African township is Diez Roux and Mair's schematic representation of the contributions of neighborhood environments to health inequalities.¹⁵ Living in a low-resource environment and the history of apartheid and residential segregation reinforce unequal resource distribution in black townships compared to the historically white urban centers. According to Diez Roux and Mair, this segregation and lack of resources leads to features of both social and physical environments which serve to affect stress and impact health, either positively or negatively; these features can include food and recreational resources, the build environment, social support, and cultural norms.¹⁵ These social and structural determinants of health, viewed within the context of the nutrition transition, serve to contribute to increasing risk of morbidity and mortality due to obesity-related chronic disease.

Residence in a low-resource community can increase one's risk for health problems: data in Cape Town showed that residents of Khayelitsha (a township outside of Cape Town) had 8,564 deaths per 100,000 attributable to NCDs, compared to rates of 450-500 deaths per 100,000 for residents of Cape Town's wealthier subdistricts.^{6,16} Residence in townships was historically required for nonwhite South Africans, under apartheid law; although racial segregation is no longer legal, poor townships remain predominately black.

Obesity-related chronic illnesses pose a significant problem to South Africa's economy, with an estimated loss to the country's GDP between 2006 and 2015 of \$1.88 billion from diabetes, stroke, and coronary heart disease.¹⁷ South African health systems, still heavily impacted by infectious diseases such as HIV/AIDS and tuberculosis, are ill-equipped to manage the expected onslaught of obesity-related chronic disease. The country has yet to make the shift from an acute care model to a chronic care model, to be better equipped to handle the growing onslaught of NCDs.

While the health and economic costs of obesity-related chronic illnesses are well-established, there remains a dearth of research on the lived experiences of individuals affected by such diseases, particularly in low-resource settings. As such, this study will investigate the health literacy of women living with diabetes and/or hypertension in the township of Khayelitsha, outside of Cape Town, South Africa, as well as the historical, environmental, and structural risk factors associated with residing in under-resourced communities like this one. Additionally, this study will assess the ways in which the presence of social support can serve to improve health outcomes for women residing in disadvantaged neighborhoods. This study will build upon the qualitative work already done by researchers such as Mendenhall and Norris, who have looked at the social origins of stress in the South African township of Soweto and its relationship to obesity-related chronic illness, as well as the healthcare experiences of women living with diabetes.^{12,18} Our study will analyze facilitators and barriers to chronic disease care in Khayelitsha, employing ethnographic and qualitative methods.

METHODS

Study Description

This study employed both qualitative and anthropologic research methods, including semi-structured in-depth interviews, focus groups, informal conversations, and ongoing ethnographic observations, which were recorded in extensive field notes. The study targeted women age 45 years and older who were overweight or obese and who had diagnosed hypertension and/or Type 2 diabetes. All focus groups were conducted with a women's group, *Iliso Labafazi* ("The Eye of the Women"), a support group for women with chronic illness.

Research Setting – Context of Khayelitsha

The research was conducted in Khayelitsha, an urban township located outside of Cape Town, South Africa. Khayelitsha, an economically disadvantaged community, is home to 391,749 people and is a predominantly Black African community (99% of the population).¹⁹ Xhosa is the predominant language spoken in Khayelitsha, though some residents also have limited English language skills. According to the 2011 Census, 45% of households live in formal dwellings, meaning a majority of the township's population resides in informal housing, and 38% do not have access to piped water within their home.¹⁹

Khayelitsha's present-day challenges are rooted in South Africa's history of racial segregation and apartheid. Racial segregation began under British colonial rule and expanded rapidly during the Apartheid Era from 1948-1994.²⁰ During this time, discrimination by race was institutionalized through a series of laws that severely limited

the rights of nonwhites. Specific to housing, a number of laws were passed which restricted cities to white populations only, forcing nonwhite populations to live in nearby townships; across South Africa, thousands of nonwhites were forcibly removed from their homes and resettled in townships.²⁰

Khayelitsha was developed in the mid-1980s; like many other townships throughout the country, Khayelitsha is located far outside the city, on the outskirts of Cape Town. Bordered by the N2 highway on the north and False Bay on the south, the township, located in the Cape Flats area, is over 30 kilometers from the city center. Although apartheid in South Africa officially ended in 1994, geographic isolation and residential segregation remain, contributing to inequalities in resource distribution, disadvantaged neighborhoods, and poorer health outcomes for the residents of these neighborhoods.¹⁵

While racial segregation persists, so too does economic apartheid: South Africa has one of the highest Gini coefficients in the world, a marker of the stark inequality that remains in the post-apartheid era.²¹ Cape Town is no different, with a Gini coefficient of 0.67, falling in the “extremely high inequality” category and indicating long-held patterns of inequity and income injustice.²² Life in the townships is often one with few job prospects and limited economic opportunity. The unemployment rate in Khayelitsha is over 38%, and over 94,000 people are not economically active; other sources cite unemployment as high as 67%.^{19,23} In addition to high unemployment, poverty is a major challenge in the community: nearly half of the households have a monthly income of less than 1,600 rand per month (approximately \$134 USD).¹⁹

In addition to high inequality and economic marginalization, Khayelitsha is marked by high crime and violence. In neighborhoods experiencing a lack of safety and persistent violence, residents undergo significant stress, which manifests itself both physically and emotionally and negatively impacts health, according to the Diez Roux and Mair's model of neighborhoods and health.¹⁵ Burdette and Hill connect this stress to increased risk of obesity: they explain that such chronic psychological distress causes the body to release adrenaline in a flight-or-flight response, which in turn triggers mechanisms which elevate cortisol levels, cause excess fat storage, increase obesity risk, and contribute to worse health outcomes.²⁴⁻²⁶ In Khayelitsha, such chronic stress is high as a result of frequent and persistent violence. Between April 2016 and March 2017, Khayelitsha had the highest attempted murder rate in South Africa, and experienced a nearly 40% increase in attempted murders from the previous year. The township ranked in the top 5 in the country for murders, and the 2016-2017 year had the highest number of murders (179) in the 10 years of available data. Khayelitsha had the second-highest aggravated robbery rate in the country, which also increased in the last year, by nearly 25%. While improvements have been made in the last year, rape and sexual assault still remains a problem in the community; theft, drug-related crimes, and burglaries are also an issue.²⁷ Such high crime and resulting persistent psychological distress can discourage physical activity.²⁴

Another feature of Khayelitsha to consider in the context of this study is the township's built environment. As an area with a mix of both formal and informal housing, some of the community is not formally planned, and as such, lacks basic infrastructure

like running water and electricity. Some streets are not paved, but rather are dirt roads. In the Town Two community in Khayelitsha, there is a local park with exercise equipment, but access to the park is often restricted by a security guard. While sports fields exist on school campuses in the community, they are locked and their use is also restricted due to safety concerns.

A grocery store is located in the Khayelitsha Mall, approximately 2 kilometers from Town Two in Khayelitsha. Most residents report walking to the store to make purchases; however, walking poses safety challenges due to frequent muggings and crime, according to our focus group data. In addition to trips to the larger grocery store, residents rely on small, informal shops or food stalls in the community -- run out of people's homes or garages -- for food purchases.²⁸ The neighborhood's physical environment, characterized by a lack of safe spaces to be physically active and a challenging and complex food environment, contribute to Khayelitsha's high obesity rates and poor chronic disease outcomes.

Instrument Development

The qualitative research guide was developed to capture barriers and facilitators to managing obesity-related chronic disease in the low-resource setting of Khayelitsha, as well as to assess the level of health literacy of the study population. We asked overweight and obese women ages 4 and older about their experiences living with Type 2 Diabetes and/or hypertension and about their health in general. The interview guide (Table 1) consisted of questions about their diagnosis with a chronic illness, their experiences with doctors and nurses at the clinic, who helps them manage their chronic

illness, how they learned about the disease(s), sources of stress in their life, and diet and physical activity habits. Questions were broadly framed and the structure of the interview was flexible. The focus group guide (Table 2) asked questions on related topics but delved deeper into each; the focus groups also included discussions about the role of *Iliso* in the women's lives. Revisions to both guides were made over time with assistance from members of the research team (other authors). The initial interview guide was pilot-tested in prior research on diabetes management in low-resource settings, previously done by the first author in Rhode Island. Members of the research team (Dr. Harrison, Dr. Cooper) provided feedback and revisions were made. All questions were reviewed and adapted to ensure cultural appropriateness for the research setting. Some of the interview and focus group questions were drawn from a qualitative research guide developed for use on diabetes care in American Samoa.²⁹

As early focus groups suggested new categories of interest, in particular about changes the women wished to see in *Khayelitsha* and other health issues in the community, modifications to the focus group guide were made. Additionally, as some early focus group questions were difficult to translate and received limited responses, questions were reframed and rephrased to be better understood and elicit further discussion.

In addition to in-depth interviews and focus groups, we employed ethnographic observation and other anthropological research methods. In the first two weeks in the field, extensive notes were taken to document the built and social environments in Town

Two, Khayelitsha, where all focus groups took place. Throughout the study, daily notes and observations were recorded as memos in an extensive audit trail (see appendix).

Participant recruitment and consent

Focus group participants were recruited from the women's group *Iliso*; all members of *Iliso* who were present in Khayelitsha at the time of the study participated. Five of the interview participants were recruited by a research assistant. The three additional interview participants were recruited through the help of the main translator.

Informed consent occurred prior to the focus groups and individual interviews. For the focus groups and three of the interviews, the translator translated the consent form from English to Xhosa. For the remaining five interviews, the research assistant explained the study and read the consent form in Xhosa. All participants gave verbal consent to participate.

Data collection procedures

The focus groups and interviews occurred over two months (July & August 2017) and were conducted by an experienced facilitator. Each focus group took approximately 60 minutes and each interview took about 25-30 minutes to complete. A translator accompanied the facilitator and translated the conversation from Xhosa to English. With some questions in the focus groups, the translator translated the individual responses as a single summary group response, for ease due to the large number of participants responding at once and speed at which the participants spoke. To ensure the accuracy of the translation and the researcher's understanding, the facilitator frequently employed reflective summaries, restating and summarizing comments provided by the participant.

A total of eight in-depth interviews and nine focus groups were completed. All interviews and focus groups were digitally recorded on an iPhone. All data were transcribed verbatim, with the help of a research assistant; data was also anonymized to protect participant privacy. The transcripts were compared to audio recordings and corrected for discrepancies when necessary.

Data Analysis

As interviews and focus groups were transcribed, an initial coding scheme was developed and notes were taken on emerging topics. Prior to coding, each completed transcription was read once and then was loaded into NVivo to facilitate analysis. Initial coding of the data was done; subsequently, the initial coding scheme was revised, making changes to code definitions, combining similar codes into one, and including any new codes that had emerged. The final coding scheme included over thirty codes. Once this list of codes was decided upon, each interview and focus group was read and coded a second time for thoroughness. A priori codes, which were based on the literature review, included: *Behavior Change*, *Demonstration of Health Literacy*, and *Knowledge Acquisition*, among others. Some of the de novo codes that emerged during the study included *Stress – Children*, *Knowledge Seeking from Facilitator* and *Lack of Role Models*. All coding and data analysis was done by the main coder (lead author). Throughout the coding process, memos were kept in NVivo to identify emerging themes. Final themes were discussed with the research team.

RESULTS

Eight in-depth interviews and nine focus groups were held over the course of July and August 2017.

Three themes and multiple sub-themes emerged from the data, which are presented below and in Table 3. Respondents discussed many barriers of successful self-management of diabetes and/or hypertension; some of these have been described previously in the literature and others which add to this body of work. We explore both these expected and previously identified challenges in Theme 1, as well as the novel findings that emerged from the data in sub-themes in Theme 1 and in Themes 2 and 3.

Theme 1 – Stress is believed to be the main cause of hypertension and diabetes.

Our study had similar findings to work done by Mendenhall and Norris in Soweto on stress and health. In their work, one-third of the sample believed that stress caused diabetes and that “stress will make you sick.”¹⁸ Similarly, our respondents frequently associated stress with their ill health: a majority of participants believed that obesity-related chronic illnesses emerged from stress. Murphy et al had similar findings, with participants in their qualitative study in Cape Town believing that hypertension is caused by emotional upset.³⁰

When asked what they believed to be the cause of their chronic illness, women repeatedly cited stress:

“Started with stress. Then painful things, yeah. That's what all started it [high blood pressure].” – IDI 7

"It [high blood] came when she was stressing about getting the children to school. So she was stressing a lot." -- IDI 5

We found that many participants did not understand how other risk factors for diabetes and hypertension, such as poor nutritional intake and physical inactivity, related to their illnesses. When asked about what contributed most to them feeling sick, they replied:

"Their children. Their children are the most stressful ones." – Iliso

Similarly, when we asked a participant why she thought her sister's health was worse than hers, she identified less stress as the difference in their health:

"Okay, maybe her, uh, the sister cause she's got children that stressing her a lot. So maybe it's not the same." – IDI 5

When rephrasing the question about causes of diabetes and hypertension, to ask participants about what they might advise their children to do to prevent chronic illness, most respondents focused their advice on stress reduction.

Women also felt that their husbands did not have hypertension because they were less stressed:

"Some of the men, they don't, like, nurse their situation when they are stressing, they just be like, 'Oh, this...' They just like, 'Ah, it will pass.' Yeah, let it go. Like, uh, men, as I said, they don't nurse like feelings, and even when we go to bed, the men is very quickly to sleep, but you, as a woman, if you are stressing, you will be like, changing, like, uh, moving [indicating tossing and turning]." – Iliso

Women believed that improvements in their health were tied to reduced stress:

"She is fine now. Her sugar is now controllable because her kids are not staying with her anymore. So she is stress free." – IDI 3

Theme 1a – Stress results from the social environment and daily challenges, including widespread community violence.

Exposure to stress is heightened as a result of one's living environment and residence in Khayelitsha. The stress felt by the women is specifically tied to the low-resource environment in which they reside. The challenges that come with living in Khayelitsha – high poverty and unemployment, crime, and violence – are felt by their children, and in turn, their mothers.

Poverty and lack of economic opportunity is a constant source of stress for the women; they worry about how to provide for their families:

"The thing that was making stress is because of the kids. They have to go to school. They have to be food. They have to... unemployed, she was unemployed. The clothes, she must buy clothes for us. Yeah, that was stressful." – IDI 7

"Sometimes we will stress about the situations that, uh, we are living in, like we are living in poverty, you see? We are not rich." – Iliso

Violence and crime in the neighborhood also cause worry and anxiety; recall that

Khayelitsha had the highest attempted murder rate in South Africa in 2016-2017.²⁷

Mothers worry about the safety of their children, as well as that of their friends' and neighbor's families:

"In the environment, it's stressing, seeing their neighbors' children may be doing something that's affecting them also... Even the neighbors are selling drugs, so it's hurtful to see children going to that house, buying drugs... So they see, when the kids are going there, and they do crime there, by her house, they do crime there." – Iliso

"We even stress about, sometimes, uh, things that happens even if it's not your child. You see something bad that happens to that particular child, but when you are at home, you just always think about that situation and stress about it. [We worry about a child] being pregnant, at a young age. Being raped and killed. Some of them, they will be stabbed, and uh, their parents, maybe they are at

work, maybe they are not around, and you are the one who is around... That is really painful, it's always stressing knowing, that "Oh, shame," you are thinking about the parents, when they come from work, like hearing these news that, 'No, your child, has passed away.'" – Iliso

With limited economic opportunity and high unemployment, children turn to drugs and alcohol:

"The most stressful thing is every weekend they [their children] go out, they drink, cuz out here it's not safe, they drink alcohol, doing drugs, they go without saying where they're going, so the mother is staying at home stressing, where the child is? There's rape, there's gangsters, so that's the most stressful thing." – Iliso

"Because once you start it [drugs], it's hard to stop. Even when the parents get sick, it's painful for the child when the mother is sick, but it's difficult for them to leave the drugs. For the lack of employment. So some of the kids go to school, to university, to colleges, but they can't find work. They are always just here... So... Lack of employment. So if they get employed, maybe it would... (trails off)" – Iliso

The structural risk factors of living in Khayelitsha manifest in their children and subsequently, in their mothers' health.

When asked about what changes they would wish to see in Khayelitsha, and what they would do differently in their neighborhood, the women had many ideas about structural changes they would make to their community. These environmental level changes included additional security on the streets, places for their grandchildren to play safely after school, and more employment opportunities for their adult children, so they would avoid the drugs and crime that plague the community. The women associated such upstream changes with stress reduction, and therefore improved health.

Theme 1b – Familial stress, including adult children living at home as part of a multi-generational household, are also a major source of stress.

Adult children were major sources of stress amongst those who participated in the study. Respondents noted that many of their children still lived at home, with multiple generations under one roof: grandmothers, children, and grandchildren. The behavior of their children caused frustration, worry, and anxiety:

“When you're angry, so you shout, you shout at the kids... Kids are drinking alcohol and smoking drugs. They come late at home, so you overthink. So you think... you're worried about them, yeah. So you, that makes stress.” – Iliso

Environmental sources of stress exacerbate stress resulting from children's behaviors.

Residing in Khayelitsha – and the associated stress from violence in the community – serves to compound familial stress. One respondent shared about a son with mental illness, who she worries about frequently. She often did not know where he was staying, and one time he had come home stabbed, with blood on his clothes.

Another respondent lost a daughter to a respiratory illness, which caused both grief and stress:

“After her daughter passed away, she was stressing a lot about how am I going to clothe the children... How am I going to feed them [her grandchildren]? So I don't have money. What am I supposed to do? So that caused a lot of stress.” – IDI 4

Women connected their stress with their ill health, especially stress resulting from their adult children:

“Then when, as old ladies, that they have kids in their house, when they are shouting at their kids, it also like makes them to be sick. When they go to the clinic, they are, what you call, their high blood is very high, because of that shouting... With their kids. Yeah, yeah. Their stress – up.” –Iliso

When the source of stress was removed – in the case of one respondent, when her children no longer lived with her – she felt that her diabetes improved:

“They [her children] were staying in her house, drinking, buying alcohol and putting it here in her house and drink. Now, she has chased them away. She is fine now. Her sugar is now controllable because her kids are not staying with her anymore. So she is stress free.” – IDI 3

While children were the main source of stress that women identified, and which posed a significant impediment to successful self-management of chronic illness, in other women’s experiences their children were a facilitator to health. Some respondents gained support in disease management from family members: for example, one woman noted that her son brings fruits and vegetables when he visits. Others said their daughters help their sick mothers around the house, and serve as sounding boards for questions about health. When asked about who she goes to with questions about “high blood” or “high sugar” and who supports her health, one woman responded:

“The kids here and the grandson. And the grandchildren. They know that she's got, uh, whenever she's not feeling well, they go quickly take the medication and give it to her... So she talk to the children.” – IDI 7

Another woman’s granddaughter helps her manage her diabetes by giving her insulin injections in the stomach. So while some women associate their chronic illness with the stress their children cause, others gain social support from family members.

Theme 2 – Low levels of health literacy resulted in limited understandings of chronic illness and prevented successful self-management.

Health literacy is defined as “the degree to which an individual has the capacity to obtain, process, and understand the basic information and services needed to make appropriate decisions regarding their health.”³¹ Participants demonstrated low levels of

health literacy in their understanding about the causes of diabetes and hypertension, associated symptoms, and proper self-management.

Many women could not identify the causes of “high blood” and “high sugar:”

“She has no idea... It's something inside her tummy that makes food doesn't... I don't know whether it does not run. But it's something here is not in the body. She can't even explain it. But it's something inside.” – IDI 3

Low health literacy was also exemplified by lack of understanding about healthy foods: one women identified rice and potatoes as healthy food to eat, not understanding that starches are to be limited by diabetics. Others noted that they cooked with Rama (a margarine spread), believing it was healthy to use.

Some of the lack of health literacy is related to women's low understanding of the perceived benefits of action to prevent or lessen the effects of diabetes and hypertension. Some women demonstrated a lack of awareness of how changes in certain behaviors may prevent the disease of lessen its severity. For example, one woman explained that she does housework as her form of exercise, but while she has been told to also walk, she does not see it as necessary:

“She does the housework. And she, she was told the walk is more important. But she doesn't do walk. She does just do the housework... She does the housework so she doesn't see why she must.” – IDI 3

To further get at the question of health literacy, we asked questions about the women's understanding of diabetes and hypertension in a variety of ways. For example, we asked the women, “If you were to tell your children things to do in your life now so that they don't get high blood and high sugar, what would you tell them?” Frequently, they would reply by saying they didn't know:

“She has no clue.” – IDI 1

“She doesn't know if she can.. Uh, block it or... (trails off)” – IDI 3

In contrast, some of the women demonstrated basic understanding of some of the causes of diabetes and hypertension and identified connections between diet and physical activity to obesity-related chronic disease. In response to what to tell her children and grandchildren to do to prevent diabetes and hypertension:

“She would tell them that they must go to gym. They must eat fruit and veg all the time to prevent.” -- IDI 4

Theme 2a – Access to health education from healthcare providers is limited and contributes to low health literacy among patients.

Low health literacy was connected to a lack of knowledge transfer from healthcare professionals to patients, and was related to barriers to receiving adequate care in local clinics.

Many respondents noted that the causes of diabetes and hypertension were never explained by their doctors:

“She doesn't know because the doctor didn't even tell her what is the cause.”
-- IDI 1

Many said they were never told of any lifestyle changes to make, besides taking medication, even though they were actively being treated for diabetes and/or hypertension:

“She does not know where this [high blood and high sugar] is coming from. So once you get it, accept it, and take medication.” – IDI 7

“They [the doctors] just left the medication to the nurses. They couldn't explain anything. So she took the medication to the nurses, then go home. They didn't tell her anything.” – IDI 1

Healthcare providers tend to rely heavily on medication for treatment, and appear to have limited time for education with their patients about lifestyle changes:

“There's no education, they just give you the medication, they only tell you the medication that, don't use these pills, use the other ones... The doctor is always rushing for the next patient, they don't have any chance to ask questions, the doctors are, they give you a card to go to the pharmacy to get your pills, or to get some more tests, but questions, no.” – Iliso

In addition to limited time with the doctor, many women pointed out language barriers with medical staff, noting that many of the doctors do not speak Xhosa, further limiting their ability to ask questions and obtain health knowledge from physicians.

Theme 2b – Even with basic health literacy and knowledge of behavior changes to make, women face self-management challenges in taking action due to structural barriers.

Some women were able to identify the links between diet, physical activity, and obesity-related chronic disease, yet they were still unable to fully explain the reasoning behind making behavioral changes. When asked questions to assess their basic health literacy – for example, *What types of South Africa foods are healthy?* – many seemed as if they were reciting what they were told or had heard from others (doctors, nurses, friends, other sources), without having a true understanding of the relationship between certain health behaviors and disease outcomes. The women have obtained some of the basic health information about diabetes and hypertension, yet are unable to process it in a way to apply to their self-management.

“If you eat--if they eat veggies, uh as the doctor said, so the, the high blood and health makes it better than the starch that the doctor said they must eat less.” – IDI 7

“She was told not to eat starch. She must not eat potatoes, carb. Butternut. No butternut. She must eat... with nonfat milk. And veg and fruit. And oats is good... It's, it's, it's her health so she has to do what the doctor says. She must eat what she is told at the clinic, that she must eat.” – IDI 3

Some women demonstrated a basic understanding of the importance of a healthy diet and regular physical activity:

“Exercise, it also helps us even when we go to the clinics, you'll hear that doctors will be saying, “Your high blood pressure, it's in the right levels,” So it's better. So yeah, that is why we exercise, most times, to help the high blood pressure, and then your body to be in the right position.” – Iliso

However, many were unable to act upon this knowledge due to structural barriers associated with living in poverty.

“We have no food. So it's also about poverty, because they want to take medication, you must eat right, veg and fruit. So if you don't have veg and fruit, that's also a big, a huge problem. So you must take medication, but also good food.” –Iliso

“Because you know, to us, to buy lot of things is difficult. So the only vegetable thing I am always eating is the spinach, cabbage. I can buy them. Not everything.” – IDI 6

“The money is the problem cause they have to buy veggies every day. So starch is the most one that is always available. Yeah, affordable. So it's making--it makes hard sometimes.” –IDI 7

Fresh food is more expensive, and in households where money is scarce and income can fluctuate over the course of the month, purchasing fresh fruits and vegetables is a challenge. Many women relied on social assistance as their sole form of income, and would buy food in bulk at the beginning of the month to save money.

“Because of the money, so if they buy rice, they buy rice for the whole month. So, if they buy spinach, they have to buy spinach now and cook it now and finish it now. So, if they cook it for dinner, even potatoes, they have to buy it as a big part of it for the whole month, so it will last for the whole month. But with the veg, they have to buy spinach, cabbage, it can't last for a month. So it's difficult. And fresh

is expensive too. It's very expensive... So if they buy apple, it cost 5 rand. So, you have to have 5 rand today and tomorrow, almost every day. So, money is not everything, is not always there.” - Iliso

Even with basic health literacy and understanding about the importance of a healthful diet in managing diabetes, the women are unable to act upon this knowledge to manage their health.

Theme 2c – Women actively sought knowledge on diabetes and hypertension, their causes, and ways to improve their health.

In many of the interviews and focus groups, the women actively sought knowledge on diabetes and hypertension from the facilitator. At the end of multiple interviews, women asked questions about how to manage their illnesses, demonstrating both a lack of health literacy, but also a strong desire to know more.

Facilitator: “Are there any questions that you have for me or that I didn't ask that you should have shared?”

IDI 3: “Um, she is asking if, how can she do, to, for her, high sugar and high blood to stay normal?”

“In your knowledge, what makes... What makes high sugar and high blood? With your knowledge.” – IDI 7

One woman asked many questions about her health and wanted to know if her knee pain was caused by her diabetes. At the end of the interview, she asked for the recording to be sent to her so that she could re-listen to the recording to replay the information the facilitator has shared.

These questions from participants also highlight the lack of knowledge transfer from health care professionals to patients, the information they are missing for successful self-management, and their desire for actionable insights to improve their health.

When the lead author's husband, a physician, visited *Iliso* and participated in a focus group, the women had opportunities to ask him questions about their health. Questions revolved around diabetes symptoms and the women's uncertainty about how best to manage them. For example,

"When she's resting she gets... [indicates hot/sweaty with hand gestures]. So she doesn't know what to do... When she feel dizzy, she doesn't feel herself when she's eating, so she eats because she's dizzy." – *Iliso*

The physician provided advice on dietary modifications to make to better manage fluctuations in blood sugar. During that exchange, the woman indicated that she no longer eats sugar and uses a sugar substitute for diabetics. However, during the conversation, she exhibited confusion about the difference between her blood sugar and sugar in her diet, making it difficult for her to understand the doctor's recommendations.

Additional questions the women asked were about their joints and arthritis. When the focus group facilitator encouraged the women to ask any additional questions they had about their chronic illnesses, they continued to focus on joint pain – perhaps because arthritis is a more pressing and present problem in their daily lives compared to complications related to diabetes and hypertension, and because the sequelae of those diseases do not immediately manifest in their day-to-day experiences. Another hypothesis is that the women's low health literacy about their chronic diseases prevented them from knowing how to begin to ask questions and seek additional knowledge from a physician.

Theme 3 – Women perceived social support as beneficial to their health and cited it as motivation for increase physical activity.

Some women knew the importance of physical activity in managing their chronic illness, yet did not perform it regularly. They identified many barriers to physical activity and many had low confidence in their ability to exert control over their physical environment. Safety and security factored into decisions to exercise.

“Uh, there is no place I can do that [walking]. Eh, sometimes I think I am lazy. Because from my location to the station, it is 45 minutes to, to go to this but I always take a taxi. The reason why, it is dangerous. You can't walk. So if you walk, you take a risk. So, some, most of the time we aren't walking, we are taking a taxi to the station.” – IDI 6

Walking or running in public was safe for men, but not for women, one said; thus, she opted to take a taxi instead of walking. Women noted robberies that had occurred in the walking path between their homes and the mall.

In the outdoor park in Town Two in Khayelitsha, lacking proper athletic attire was a barrier to exercise:

“Mama was crying because she didn't have tracksuit, takkies and tracksuit, she went there with sandals, they turned her back. No skirt. So she was crying.” – Iliso

The woman was chased away by security guards who would not let her exercise in her traditional skirt (worn by married women); without sneakers and athletic pants (which are expensive and beyond her budget), she was turned away. The women also noted that they did not exercise in winter, because the places to be physically active in Khayelitsha are all outdoors. During cold, rainy winter months, they do no exercise outside.

Despite these hurdles, social support allows women to overcome many of the structural barriers to physical activity in Khayelitsha. Specifically, the women who were part of *Iliso* had a strong social support network that encouraged group exercise. The women repeatedly noted that they enjoyed exercising together, and that it made them feel “fresh.” After exercising,

“You don’t feel any pain. It’s like, your body, it’s not weak anymore. You feel young! Your body becomes light! (laughing). You don’t feel anything.” – Iliso

“Even like, even having a group like Iliso, laughing, to us, it’s part of exercising, laughing, because we are talking, laughing, so we enjoy each other’s company.” – Iliso

The women of *Iliso* exhibited a genuine passion for soccer, a sport they frequently play together:

“And the reason, us, we were doing it [soccer]. It’s because we love what we were doing, so you have to love something. You have to fall in love with that thing you are doing, you see?” – Iliso

The power and importance of the group dynamic was evident when the lead author facilitated a donation of athletic attire for *Iliso*. The women requested all the same color athletic tops – they wanted to match and strongly identified with being part of a team:

“Then when they have money, they will write it [on the back of the shirts] – Iliso, so that’s why they want it all the same.”

When asked about the best things in their life, the women of *Iliso* remarked that being part of the group was one of the things they valued most. Being physically active together was a source of joy and an escape from the stressors of daily life:

“Exercising [is the best thing in their life]. When they exercise, they laugh a lot together. So that makes them happy.” -- Iliso

Even in the wake of structural barriers to physical activity in Khayelitsha, the women of *Iliso* remain active, due to the social support they gain from being part of the group:

“We don't give up because, us, we believe that we are exercising, and it also helps our health.” – Iliso

For those women not part of a support group like *Iliso*, there was a lack of social modeling for appropriate ways for older women to exercise. Those without role models and knowledge and skills about physical activity engaged in it less. For example, one respondent said:

“She doesn't go to the gym. She never saw, women, like uh, of her age, going to the gym, so she just stays at home. No gym at all.” – IDI 2

As a young girl, one woman noted that she played soccer and netball at school. But, “now they become old, they don't do that.” Another said, “There's no way. Nah exercise.” One woman noted that exercise was a white woman thing to do, and not something that black older women did.

“Old, white women, they are very fresh cause they do exercise, but not them. But not the, the black ones.” – IDI 2

Without role models and social support, most interview participants did not engage in regular physical activity. However, the social support gained by being part of a group like *Iliso* promoted physical activity and increased self-efficacy, even in the wake of structural and environmental barriers to exercise.

DISCUSSION

Our findings indicate that older women in Khayelitsha living with diabetes and hypertension have low health literacy about the causes of their chronic diseases and the

best practices for successful self-management. Stress was identified as the main cause of these illnesses, much of which originates from their adult children, who live at home in multigenerational households. Familial stress caused by adult children is directly connected to the risk factors associated with residing in an under-resourced neighborhood like Khayelitsha.

Adult children lack economic and job opportunities and frequently turn to drugs and alcohol in this vacuum, placing emotional stress on their mothers. Finances also create stress, as these women assume the primary caretaker role for their grandchildren and must serve as the matriarch, with extremely financial limited resources. The neighborhood disadvantage and community-level stress in Khayelitsha, a result of widespread poverty, high unemployment, and high crime, collectively contribute to the women's chronic psychological stress, which manifests in the body as physiological stress in the form of obesity, diabetes, and hypertension.¹⁵

When assessing health outcomes in Khayelitsha, one cannot ignore the history of apartheid and institutionalized racism in South Africa. The racial segregation and resulting inequities in resource distribution directly led to Khayelitsha's poor built environment, which has been severely under-resourced for decades, even after the fall of apartheid, and is not conducive to good health outcomes. Exposure to a built environment lacking safe places to be physically active, and to a food environment with limited access to fresh fruits and vegetables and easy access to high-caloric and low-nutrient foods, increases risk for obesity-related chronic disease.

Despite the structural risk factors associated with residence in Khayelitsha and the many environmental barriers to health that they face, the women in this study identified many facilitators to health and disease self-management. Social networks serve to aid in health promotion – for example, some women drew upon assistance from family members, who aided in disease management by purchasing nutritious food and providing assistance with medication administration and general care.

Social networks were also an important source of social support, in particular through tight-knit groups like *lliso*. Social support gained from being part of a group may serve to improve self-efficacy for physical activity, even in an environment that is generally not conducive to it. Social support was cited as helping women to overcome barriers to exercise, such as a lack of knowledge of how to exercise: women were physically active together and learned from each other enjoyable, age-appropriate, and gender-appropriate ways to be active. Additionally, women walking together as a group may improve perceptions about the safety of physical activity, in the wake of concerns about safe places to recreate due to crime and violence. Social support also importantly promoted both stress relief and a love of sport, through laughter and having fun with fellow group members. Women who did not have strong social support networks generally responded that they were less physically active – it appears that they either did not have role models to demonstrate appropriate ways for women like them to exercise, or did not have the self-efficacy to exercise, even when they knew the health benefits of it.

CONCLUSION AND RECOMMENDATIONS

Women's health in Khayelitsha is strongly impacted by social determinants of health, including poverty, unemployment, and environmental conditions resulting from decades of institutionalized racism and unequal resource distribution. In the absence of upstream interventions to address these health determinants, interventions targeted at the community and interpersonal levels could be effective ways to promote improved chronic disease self-management. Programs and policies aimed at building social networks and improving social support may be the most effective tool to promote physical activity as a strategy for self-management in low-resource communities like Khayelitsha, where changes at the environmental level may be slow to come. Additionally, identifying community leaders, who could be trained in the areas of nutrition and physical activity and could serve as role models for diabetes and hypertension management, could be an approach to improve health literacy. Future research should continue to investigate the ways to which social support can lead to better self-management of obesity-related chronic conditions in low-resource environments.

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TABLE 1. Sample of Interview Questions

<i>Interview Questions</i>
• How do you feel your health is and what issues do you have with your health right now?
• When the doctors told you about having high blood and high sugar, how did that make you feel?
• How did you first learn about high blood and high sugar?
• How has your life changed since you got sick?
• What in your life causes you to feel stressed?
• What do you think can improve your health and make your symptoms from high blood and high sugar better?
• What would you tell your children to do in order to not get high blood and high sugar in the future? What can you do to prevent it?

TABLE 2. Sample of Focus Group Questions

<i>Focus Group Questions</i>
• <i>What types of South African food are healthy, and which are unhealthy?</i>
• <i>If money wasn't a problem, what types of foods would you buy more of and cook more of?</i>
• <i>How did you learn about healthy cooking and healthy eating? Where did you learn about it and who taught you?</i>
• <i>What are ways that you like to exercise? How did you exercise when you were younger, and are there different ways that you like to exercise now that you are older?</i>
• <i>When you are feeling stressed, what are things that you do to make yourself feel better?</i>

TABLE 3. Themes and Sub-Themes

Theme 1
<i>Stress is believed to be the main cause of hypertension and diabetes.</i>
1a. Stress results from the social environment and daily challenges, including widespread community violence.
1b. Familial stress, including adult children living at home as part of a multi-generational household, are also a major source of stress.
Theme 2
<i>Low levels of health literacy resulted in limited understandings of chronic illness and prevented successful self-management.</i>
2a. Access to health education from healthcare providers is limited and contributes to low health literacy among patients.
2b. Even with basic health literacy and knowledge of behavior changes to make, women face self-management challenges in taking action due to structural barriers.
2c. Women actively sought knowledge on diabetes and hypertension, their causes, and ways to improve their health.
Theme 3
<i>Women perceived social support as beneficial to their health and cited it as motivation for increase physical activity.</i>

From Community Health Workers to Community Health Coaches: An Intervention to Reduce Sedentary Behavior to Address Obesity-Related Chronic Disease Amongst Older Women in a South African Township

BACKGROUND

Infectious diseases like HIV and tuberculosis have historically been considered among the most pressing public health problems for developing countries in sub-Saharan Africa. However, as low- and middle-income countries (LMICs) on the continent go through the nutrition transition, non-communicable diseases (NCDs) such as Type 2 diabetes and hypertension are becoming increasingly prevalent and problematic. Data shows that since 2010 in South Africa, NCD deaths have outnumbered those attributable to communicable diseases, and that women are especially at risk, facing a great NCD burden than men.^{1,2}

In South Africa, chronic diseases are increasingly contributing to mortality. Data from the WHO show that in South Africa in 2014, cardiovascular diseases accounted for over 100,000 deaths (18% of all deaths), while diabetes accounted for over 36,000 deaths (6%).³ Prehypertension and hypertension prevalence have been estimated at nearly 40% in adults age 15 years and older, while an estimated 2 million people have diagnosed diabetes.^{2,4} The burden of high blood pressure is especially high among older adults: nearly 75% of adults age 50 and older were found to have hypertension.⁵

NCDs place a greater burden on South African women: in looking at self-reported rates of NCDs, 20.6% of females reported high blood pressure, compared to 12.0% of males, and 6% of females self-reported high blood sugar, compared to 4% amongst males.² Between 1999 and 2006, premature deaths among adult females due to hypertensive heart disease increased from 14 per 100,000 to 17 per 100,000, a 20% increase, while deaths associated with diabetes increased by over 40%, from 23 per 100,000 to 33 per 100,000.⁶ Additionally, women face a disproportionate burden of the risk of overweight and obesity, important risk factors for diabetes and hypertension. The prevalence of overweight and obesity among women is 25% and 40.1%, respectively, compared to 19.6% and 11.6% among men.²

With the rising prevalence of NCDs, LMIC health systems must begin to face the dual burden of treating both infectious and non-communicable diseases; however, many are ill-equipped to adequately manage NCDs.^{7,8} Limited resources, poor and inadequate healthcare delivery, and a focus on acute care over chronic care all contribute to NCDs being a secondary priority in LMICs healthcare systems.⁹

With health systems that are unprepared to deal with the increased burden of patients with NCDs, public health practitioners in LMICs must look to alternate models of care to help patients manage their chronic illnesses. One such strategy draws upon best practices for NCD management in high income countries (HICs), in particular physical activity interventions to address high prevalence of overweight and obesity and its sequelae; such interventions can be

adapted and made culturally relevant for implementation in countries like South Africa. Another promising path is to assess how lessons learned from HIV care models in South Africa might be applied to NCDs for successful chronic disease self-management. Much has been written about how to integrate HIV and NCD care to address comorbidities; however, here we will focus on the ways in which the adherence club and support group model, which has been successful with HIV in improving adherence, can be replicated in NCD management.

Literature Review: Lessons from HIV

With the advent of new treatments for HIV, persons with the disease are now living longer; as such, the management of HIV now mirrors long-term NCD care, and HIV can be considered the first extensive chronic care program in low-resource settings.^{10,11} Both HIV and NCDs require ongoing appointments with healthcare providers, medication adherence, and long-term disease self-management, among other similarities in care.¹¹

Lessons learned from HIV interventions can thus be applied to NCD management, to develop an integrated chronic disease management (ICDM) model.^{12,13} Such a model draws on innovative approaches employed in HIV care, including task-shifting from doctors and nurses to community health workers (CHWs), who work with patients to improve disease counseling, patient education, and community engagement.¹³ Another method that has been found to be successful in improving HIV medication adherence and improving viral load suppression is the use of patient adherence groups or clubs, where CHWs or experienced patients – peer educators – lead group discussions on self-

management of HIV.¹¹ In a study in Khayelitsha, Cape Town, South Africa, which compared the adherence club model of care to the standard model (in which patients were treated individually by a nurse or doctor), researchers found that club participation was associated with viral load suppression and improved ART retention.¹⁴ The methods and strategies employed include the use of positive role models for positive reinforcement of behavior change, specifically adherence to medication, as well as peer education, the use of community health workers, small-group discussion, and the mobilization of social support through new social network linkages. These methods appear to be effective in improving adherence: 97% of adherence club participants remained in care, versus 85% among those receiving standard care.¹⁴ Not only are such clubs demonstrating better retention rates, they are also cost-effective: another study in Khayelitsha showed that clubs have lower annual costs than standard care, and qualitative findings indicate higher patient satisfaction with club services due to shorter travel time to clubs and shorter wait times.¹⁵

Leveraging best practices both from the HIV treatment experience as well as from physical activity interventions in high-income countries, we outline an intervention to address obesity-related chronic disease in South Africa. Specifically, this proposed intervention aims to improve self-management of diabetes and hypertension among women ages 45 years and over living in Khayelitsha, affecting changes at the psychosocial, behavioral, and clinical levels.

Intervention Setting: Barriers to Diabetes and Hypertension Self-Management in South Africa

It is generally accepted that the adoption of a healthy lifestyle is key to helping manage diabetes and hypertension. Yet to understand the barriers our target population faces in eating a healthy diet and being physically active, we must first consider a series of environmental and social risk factors, specific to the South African context.

First, South Africa is in the midst of the nutrition transition, with a shift in dietary patterns toward a most Western diet of higher-calorie, less nutrient-dense foods. A literature review on changes in diet amongst black urban South Africans found that over the past 50 years, fat intake has increased from 16.4% to 26.2% of total energy.¹⁶ Meanwhile, a cross-sectional study of 1751 adults ages 15-80 years in South Africa's North West Province documented evidence of the nutrition transition as early as the 1996; the study, which utilized a culturally sensitive food frequency questionnaire (FFQ), found low mean intakes of micronutrients, low fruit and vegetable consumption, and amongst urban residents, higher fat and refined carbohydrate intake.¹⁷

This change in diet is accompanied by a shift in physical activity patterns, toward lower levels of energy expenditure and increased sedentary behavior.^{18,19} South Africa is experiencing low levels of physical activity: prevalence of low physical activity has been estimated at 60%, and nearly half of all women in South Africa are unfit.^{2,20} High rates of physical inactivity in South Africa is generally associated with industrialization and urbanization, where a changing

economy, job market, and transportation infrastructure lead to increasingly sedentary behavior at work and in transit.²¹ Low physical activity levels, in conjunction with a shift to a more Western diet of energy-dense, low-nutrient foods, is of grave concern, especially considering the growing prevalence of obesity-related chronic disease.

A social determinant of health to consider is the historical context of apartheid in South Africa, and the legal actions of the apartheid government which still today have lasting effects on black South Africans. Racial segregation laws passed during the apartheid era, which forced black South Africans to reside in townships, continue to define urban residential demographics today.²² Khayelitsha, which like many townships is geographically segregated, is located far from its urban core of Cape Town and is 99% black.²³ Township residents face poor job prospects and high poverty: one source found that 19% of Khayelitsha residents report no source of income.²⁴ Khayelitsha is comprised of both formal and informal settlements, with over half of the region's residents living in informal dwellings.²⁴ Low socioeconomic status and living in poverty convey risks of adverse health outcomes in the target population.

Finally, one must also take into account South African attitudes about healthy body weight and perceptions of beauty and their effect on obesity-related chronic disease. Amongst black South Africans, social and cultural norms around beauty and body image impact environmental conditions that support maintaining a healthy body weight. 88% of South Africans indicated that “fat” was their ideal body image.² Being overweight is considered a sign of good health, beauty, and

affluence, while being of a lower body weight is perceived as being associated with unhappiness, personal problems, and HIV infection.^{25,26}

In Khayelitsha, being overweight or obese is desirable: in a qualitative study, women reported that 'fat' is considered sexy.²⁷ Large women are perceived to be more respected and dignified, and once married, women are encouraged to gain weight as a marker of her husband's ability to provide for her financially: Khayelitsha men often praise their wives for their larger size.²⁸

Such preferences for higher body weight are seen even amongst community health workers CHWs. A qualitative study of CHWs in Khayelitsha found that there is a stigma associated with thinness and exercise, evidenced by this quote from a CHW: "If we exercise, we will lose weight and what will people think about us?"²⁹ There is a lack of health literacy around what is defined as overweight and obese – less than half of overweight women actually perceived themselves as being overweight.²⁵ Cultural perceptions of beauty and definitions of a healthy weight can be considered risk factors for overweight and obesity, and by extension diabetes and hypertension.

Gender norms also come into play: in some areas of the country, it is less culturally acceptable for black South African women to wear tight-fitting clothing, such as track pants, when being physically active.²⁵ Additionally, there is also a perception that women participating in leisure-time physical activity takes away from time that could be spent doing household chores.²⁶

Understanding the specific risk factors experienced by older black women in Khayelitsha, we now explore the details of our proposed intervention.

FRAMEWORK FOR INTERVENTION

Specific Aims

- To develop a culturally appropriate, evidence-based, theory-driven intervention to address Type 2 diabetes and hypertension, reduce sedentary behavior, and promote physical activity amongst overweight and obese women ages 45 years and older living in Khayelitsha, Cape Town, South Africa.
- To assess behavior change, with regard to sedentary behavior and physical activity (primary outcomes), and diet (secondary outcome); and psychosocial change, with regard to self-efficacy,
- To measure changes in clinical outcomes, including cardiovascular fitness, BMI (via weight loss), waist circumference, blood pressure, and HbA1c levels,
- And to improve self-management of diabetes and hypertension amongst the target population.

Needs Assessment and Preliminary Results

A needs assessment was conducted via the collection of formative research. A qualitative study with older women living with chronic disease was completed in Town Two in Khayelitsha in 2017, the results of which have been reported elsewhere.³⁰ Qualitative data was collected through a combination of ethnographic observation, in-depth interviews, and focus groups with a women's group, *Iliso Labafazi* ("The Eye of the Women"), a support group for women with chronic illness. Some of the key findings were that women exhibited low levels of

health literacy and had limited ability to connect basic understanding about chronic illness to actionable steps for successful self-management.³⁰ Even when women possessed basic health literacy about diabetes and hypertension and had knowledge of behavior changes to make, they faced self-management challenges in taking action due to structural barriers related to residing in Khayelitsha. Environmental and structural factors impeded women's abilities to act on their knowledge and adhere to health recommendations. Importantly, it was found that being part of a support group like *Iliso* increased social support and improved self-efficacy for physical activity, even in an environment not generally conducive to it. However, those not part of a support group, without role models and the knowledge and skills about physical activity, engage in it less.³⁰ Building off of the findings from this formative work, we outline the desired behavioral outcome of the proposed intervention.

Behavioral Outcome

The desired behavioral outcome of this proposed intervention is that the target population will *reduce their sedentary behavior*. Many health risks are associated with sedentary time; among adults, sedentary behavior is associated with increased risk for diabetes, hypertension, cardiovascular disease, and metabolic syndrome, along with many cancers.³¹ Sedentary behavior is defined as behaviors that involve sitting and low levels of energy expenditure, usually less than 1.5 metabolic equivalents (METs); this may include time spent watching television or engaging in screen-time on a cellphone.³¹ For the purposes of this study, a reduction in sedentary behavior will be defined as a decrease in average

sitting time and an increase in regular physical activity, such as walking, running, or other aerobic exercise, to reduce the risk of onset of or complications from diabetes and hypertension.

Theoretical Framework

This intervention proposal draws upon two main behavioral theories: the Health Belief Model and Self-Determination Theory.^{32,33} The Health Belief Model (HBM) can be used to explain people's perceptions about the seriousness and severity of health problems, as well as the perceived benefits of performing a specific action, such as engaging in physical activity. HBM can also help understand people's perceived barriers to performing health actions. Self-Determination Theory (SDT) refers to motivations to behave (or not behave) in healthy ways. One of the constructs we utilize from SDT is competence, which here refers to competency in performing physical activity; we also use the construct of self-efficacy, from both HBM and SDT, which refers to the level of confidence that a person has about his or her ability to perform a health-related behavior. These two theories informed the development of the intervention determinants, methods, and strategies, which follow.

Determinants

Determinants are the factors that explain why a person may perform or not perform a certain behavior – in our case, reduced sedentary behavior and regular physical activity – and can be both personal and environmental.

One of the reasons why older women in Khayelitsha may not engage in regular physical activity is because of a lack of knowledge around how to

exercise, as well as a lack of self-efficacy. A qualitative study on diabetes self-management in Cape Town, South Africa, consisting of 22 interviews with hypertensive and diabetic adult patients, found that patients had a lack of understanding of the causes of diabetes, as well as a lack of knowledge of lifestyle modifications to make, such as increasing physical activity.³⁴ A lack of confidence and competency around how to modify their lifestyle was also found: low self-efficacy and a lack of knowledge of ways to exercise outside of housework and walking can serve as barriers to physical activity. These findings are supported by our formative qualitative research.³⁰

Relatedly, women in this setting may also not engage in regular physical activity because of beliefs about the benefits of it.³⁵ Especially among older adults, who grew up during a time period when exercise was not as common as today, awareness about the role of physical activity in health is low.³⁵ In our formative research, when asked about how they exercised as young girls, some women responded that they did not exercise, because they were already physically active through regular life activities such as fetching water or farming.³⁰

Due to low health literacy, women may not engage in regular exercise because they do not believe that it can help prevent the onset of or reduce the severity of diabetes. Some women demonstrated a lack of awareness of how changes in certain behaviors may prevent the disease or lessen its severity. In our formative research, one woman explained that she does housework as her form of exercise, but while she has been advised by healthcare providers to also walk, she does not see it as necessary:

“She does the housework. And she, she was told the walk is more important. But she doesn't do walk. She does just do the housework... She does the housework so she doesn't see why she must.” – IDI 3³⁰

Beliefs about personal safety are also associated with not performing regular physical activity. Our formative research found that women do not walk to the supermarket, preferring to take a taxi, due to safety concerns; robberies and violent crime were cited as reasons not to walk the path from their homes to the supermarket.³⁰ In another qualitative study in Khayelitsha, which utilized a body mapping technique, group discussions, and interviews to understand how black South African adults ages 18-60 perceived the impact of their environment on their health, a respondent reported that local parks were not safe to use due to vandalism, and drug and gang activity.³⁶ Women noted that they can only safely walk on main roads and the roads immediately around their residence, otherwise they risk getting robbed:

“It's not safe to go there because sometimes when we are walking these kids will apprehend us... if you have whatever little money with you they can even snatch that from you, even if it's just R10, they will take it.”³⁶

Finally, women may not engage in regular physical activity because they do not expect that performing the behavior will actually reduce risk or severity of diabetes and/or hypertension, or they do not perceive that they are at risk for chronic disease in the first place. A study of over 13,000 adults in South Africa assessed self-perceptions of body size and found that overweight and obesity was underestimated, and in a sub-group analysis, found that the least-educated population showed the greatest discrepancy between perceived and actual BMI.³⁷ Perceptions were far from reality: 9.7% of men and 22.1% of women

identified themselves as overweight, however in actuality 29.2% of men and 56.6% of women were overweight or obese.³⁷ With such a wide gap between those who are overweight or obese and those who perceive that they are, there is a lack of understanding among many South Africans of the risks they face for developing a chronic disease associated with excess adipose tissue.

Methods and Strategies

Our methods and strategies draw upon best practices that have been established through interventions that have been shown to be effective in improving physical activity outcomes and reducing weight in high income countries. Here, we outline a number of interventions that have demonstrated efficacy.

Best Practices from Successful Physical Activity Interventions done in HICs

In a study conducted between 1997-1999 near Sydney, Australia, researchers investigated the effects of a community-based intervention aimed at promoting physical activity amongst women ages 20-50 years.³⁸ As part of a larger social marketing campaign within the intervention, community walking groups were formed. Researchers assessed physical activity through self-reported amounts of moderate to vigorous physical activity (MVPA); based on this self-report data, they subsequently classified participants as sedentary, low active, moderately active, or highly active.

In 1,801 post-intervention surveys, the study demonstrated an increase in activity levels: they found a reduction in the proportion of women in the sedentary category, from 22% in the pre-intervention survey to 15% post-intervention. In

addition, qualitative findings indicated psychological benefits: participants reported that being active was a “time out” from life, a social outlet, something that gave them more confidence, and which enabled them to better cope with life stresses. They further noted physiological improvements, including weight loss, more energy, and feeling younger.³⁸

While this study demonstrates many self-reported benefits of community walking groups, including reductions in sedentary behavior, it is not without limitations. One, all the data is self-reported, with no clinical measures captured. Two, the authors found no statistically significant increases in reported number of hours spent walking. Also, results may not be generalizable to our target population, as participants in this study were generally younger, had high health literacy, low unemployment (only 3% of the study population was unemployed), and felt safe participating in physical activity (90% reported that they felt safe walking during the day). Despite these limitations, the qualitative findings about the benefit of community walking groups – and the social support they appear to provide -- are promising.³⁸

In another study – a randomized clinical trial assessing the effect of a lifestyle intervention program on the prevention of weight gain amongst women ages 44-50 years – Simkin-Silverman and colleagues demonstrated the success of a small support group model for delivery of the intervention in controlling weight.³⁹ This RCT was conducted in Allegheny County, Pennsylvania between 1992-1999 and consisted of a 54 month lifestyle intervention; 265 women were in the control group, compared to 260 in the intervention arm. Those in the

intervention arm participated in two phases of intervention: one, 15 small-group meetings of approximately 20 women, held over the course of 20 weeks; and two, group meetings every few months, held over the following 4 years, as well as a 6-week refresher course. Phase one was focused on education about healthy lifestyles; women set a weight loss goal and were encouraged to increase their physical activity to 1,000-1,500 calories expended per week, to facilitate weight loss. Phase two meetings covered various health topics, and the refresher course included exercise classes and group walks.³⁹

Simkin-Silverman and colleagues showed a greater prevention in weight gain (defined as changes in weight relative to baseline) in the intervention arm compared to the control (55% in the experimental group were at or below their baseline weight at study conclusion, compared to 26% in the control group). Relatedly, they saw a greater decrease in waist circumference and better long-term physical activity adherence in the intervention versus control group. The robust findings result from the RCT study design, an extensive and long-term lifestyle change program, and the utilization of sound measures (physical activity was assessed through the Paffenbarger Activity Questionnaire and the use of activity monitors).³⁹ While our proposed intervention will not have such vast resources nor such a long follow-up period, we hope to draw upon the methods from phase 1 of the intervention to demonstrate similar shorter-term findings in sedentary behavior reduction, physical activity promotion, and weight gain prevention.

A physical activity intervention targeting adults age 50 or older across the United States provides further evidence of success of group-based interventions. The Active Living Every Day (ALED) program was implemented by five community-based organizations across the US, including in some low income settings, as part of a study to evaluate the translation of an efficacious intervention into practice.³⁸ The 20-week ALED program utilized a group design to deliver behavior change curriculum and provide social support to participants, a majority of whom were older women (average age 68 years, 80% of participants were female). Using self-reported data (an acknowledged limitation) collected through 333 post-program surveys, the authors demonstrated statistically significant increases in MVPA and total physical activity among participants: MPVA increased by 2.12 hours per week over baseline, and total physical activity increased by 3.84 hours per week over baseline.³⁸ However, they were unable to show long-term effects as the self-reported data was collected at the end of the program.

Best Practices from Physical Activity Interventions in Low-Resource Settings

In addition to lessons learned from interventions implemented in HICs, we can also draw knowledge from interventions targeting populations in low-resource settings, which share similar challenges to at-risk populations in South Africa. The intervention “Pasos Adelante,” or “Steps Forward,” was implemented in impoverished communities along the US/Mexico border, with a focus on chronic disease prevention.⁴⁰ The program employed community health workers (CHWs) to lead the 12-week prevention program, which included weekly 2-hour

sessions with educational components, goal-setting, a walking club, and sessions on nutrition, physical activity, and chronic disease prevention.

Results from Pasos Adelante were promising: 87% of participants completed the 12-week program, and self-reported outcome data showed a 120-minute median increase in moderate walking after 12 weeks in post-program surveys, compared to pre-program levels of physical activity.⁴⁰ Findings from this study are especially relevant to our proposed intervention because the target populations have many similarities. Participants in Pasos Adelante were of similar age (average age 49.5 years) and lived in communities facing high rates of poverty and unemployment, with a high prevalence of diabetes (18%), and lacking in safe places to exercises; additionally, participants faced environmental barriers to physical activity due to extreme heat. Our target population in Khayelitsha has similar socioeconomic challenges and health disparities. We hypothesize that methods and strategies employed in Pasos Adelante will be generalizable and applicable to our intervention.

Another strength of the Pasos Adelante invention was the use of community health workers – in this particular case, *promotores* -- to deliver the program. CHWs have been shown to increase access to care, especially among underserved communities.⁴¹ CHWs have been employed to help address the challenges of providing HIV care, and the utilization of CHWs in HIV has been met with much success. A systematic review of the use of CHWs in sub-Saharan Africa found that CHWs helped to improve the reach, utilization, and quality of HIV services, as well as improve care retention and overall quality of life of

patients.⁴² CHW interventions to address diabetes care have been shown to improve the health status, physical activity, dietary habits, and medication adherence of diabetic patients.⁴³ A randomized trial to assess the effectiveness of a CHW intervention amongst 189 Hispanic diabetic patients living in an inner-city found that compared to the control group, patients receiving the intervention had 2.9 times greater odds of decreased BMI.⁴³ CHWs appear to be a successful model of care for chronic diseases and can improve both clinical outcomes and overall quality of life for patients.

There is limited literature on physical activity interventions in South Africa, but it is important to develop our methods and strategies from what little does research exist. A study in South Africa of men and women ages 40-65 years with Type 2 diabetes evaluated the effectiveness of a physical activity and diet intervention on HbA1c levels.⁴⁴ Inclusion criteria included having type 2 diabetes for at least one year and an HbA1c between 8-9.5%. Participants were randomized into either the experimental or control group. In the intervention group, patients received educational programming through four weekly group sessions, employing methods including the development of new social networks and consciousness-raising, with the control group received standard care. Participants tracked their steps and utilized goal-setting and self-monitoring via pedometers and a logbook. Verbal persuasion was also employed through motivational text messages sent to participants every 2 weeks. While the study utilized interesting methods and strategies, they did not appear to be particularly effective in the long term; decreased HbA1c levels in the intervention group were

found at 16 weeks but not at the 1 year follow up. Other study limitations were the small sample size (n = 51) with some loss to follow up (43 participants completed the study).

Based on the literature about successful physical activity interventions and utilizing best practices from HIV treatment, including the use of CHWs, the main methods our proposed intervention draws upon include:

- **Group-based health programming**, to build social support, and,
- **Modeling**, through the use of peer role models demonstrating successful self-management through regular physical activity, and,
- **Guided practice** of physical activity, with a peer coach to increase knowledge and skills about physical activity.

Intervention Components – Community Health Coaches

The intervention will consist of a number of components aimed at addressing different determinants. The main part of the intervention will be peer-led chronic disease support groups, drawing on the success of this care model that has been demonstrated with HIV. Within these support groups, community health workers will act as peer leaders and role models, which will be a key feature of the intervention: peers who are successfully managing their diabetes and hypertension will lead the support group in discussions about tips and strategies for successful self-management. Within support groups, members can share ways that they are incorporating regular walking (a desired health outcome) into their daily lives. Peer role models will serve as community health coaches – similar to community health workers, but in a coaching role with a

specific emphasis on nutrition and physical activity. Community health coaches can be more accessible and relatable than health care professionals; as such, their gain-framed messages about the benefits of physical activity may be better received by the target population.

Support groups, or clubs, will meet once per week for two hours over the course of one year, following a similar model of weekly meetings utilized in the *Pasos Adelante* intervention.⁴⁵ Meetings will be held in a local church in Town Two in Khayelitsha, where the pastor has already given permission for meetings. During the weekly sessions, the first thirty minutes of the session will be dedicated to the delivery of educational curriculum from the community health coach, while the second thirty minutes will be a question-and-answer session, where group members can ask questions of the coach and of the group and share tips and advice. The final hour of the session will be specifically focused on physical activity practice, including demonstration of skills by the coach, including stretches and strengthening exercises, and group physical activity, including group walks.

Doctors and nurses from the local clinic will help identify potential community health coaches who demonstrate successful chronic disease management through diet and physical activity and will facilitate initial orientation of the coaches to help them serve as successful role models. As part of the orientation, coaches will undergo two weeks of full-day training sessions before leading a support group. Training sessions will be led by a certified personal trainer with experience in physical activity promotion, as well as by a registered

nurse with experience in diabetes and hypertension care. Both the trainer and the nurse should share the cultural background of the trainees, and all training will be conducted in Xhosa (the main language spoken in Khayelitsha) to facilitate understanding by the trainees. Upon completion of the three training sessions, coaches will take a quiz to assess their health literacy on diet, physical activity, and chronic disease, as well as their preparedness to lead a support group. Should a coach not score high enough on the quiz to demonstrate proficiency, the coach will undergo additional one-on-one training with the certified personal trainer and registered nurse until they are deemed qualified to lead a group.

Such rigorous training of coaches prior to leading a support group is necessary because previous qualitative research has shown that CHWs in Khayelitsha lack understanding about the causes of, recommended treatment for, and suggested lifestyle modifications for hypertension.⁴⁶ Additionally, other work in Khayelitsha has indicated that CHWs show a preference for larger body sizes; though some CHWs were aware of the negative health consequences associated with obesity, among those who had tried to lose weight, few had utilized physical activity as a strategy.²⁵ While CHWs have been shown to play an important role in successful chronic disease management, adequate training is vital.^{47–49} In Khayelitsha, a study assessing training of CHWs found that a one-week training on CVD risk factors was not sufficient: less than half of the trainees in the study had a sufficient score on the post-training test.⁵⁰ When a second week of training was added to the CHW curriculum, 87% of trainees passed the

test; as such, our training of coaches will take part over two weeks to ensure adequate time for knowledge acquisition.⁵⁰

Support group participants will be recruited from the local clinic; at diabetes and hypertension appointments, nurses and clinic staff will advertise the support group to patients to help recruit participants. Groups will ideally consist of 7 members plus 1 peer leader. At the first group meeting, all members will make a public commitment to each other to regularly attend meetings, openly share, and to support each other.

Support groups will not only provide learning and skill acquisition through peer modeling, but also through educational materials to increase knowledge.

Flip charts and posters will be provided to peer leaders for use in group meetings; all written materials will be in Xhosa to ensure accessibility and all materials will be culturally appropriate for the target population. Educational topics covered during weekly sessions will include: healthy eating, strategies to reduce fat and caloric intake, stress management techniques, benefits of physical activity, problem-solving to overcome diet and physical activity challenges, and diabetes and hypertension self-management strategies.

Educational content will draw upon curriculum developed by the US Center for Disease Control for the National Diabetes Prevention Program, a lifestyle change program shown to be effective at teaching behavior change techniques that promote weight loss; curriculum will be culturally and linguistically adapted for use in a setting like Khayelitsha.^{51,52} Coaches will be provided with a script to

assist them in the delivery of educational content, to ensure that the curriculum is delivered uniformly.

During weekly group meetings, participants will set personal goals for physical activity, make a public commitment to these goals, and will monitor their progress through pocket-sized log books. During the second half of each session, the community health coach will focus specifically on physical activity coaching: through guided practice and verbal persuasion, the coach will demonstrate culturally-appropriate exercises for the target population and lead the group in an exercise session. The training sessions with this credible source will not only enhance skills but also promote a sense of community and forge shared connections amongst group members.

Study Design

The intervention will be a prospective cohort study, with a cohort in Khayelitsha that is “exposed” to the intervention and a similar cohort in which is “not exposed” and thus does not receive the intervention. Participants will be recruited from two clinics in Khayelitsha, Site A Clinic and Site B Clinic. Participants from Site A will be added to five 8-person support groups and will receive the intervention, while Site B participants will not be placed in support groups. Participants from both clinics will receive the medical standard of care for type 2 diabetes and hypertension, while Site A participants will receive the intervention in addition. We will take baseline health data on the clinical outcomes of interest and follow the two populations for 1 year; we will also request access to medical records for primary care check-ups and follow-up

appointments during the study period. Additionally, we will gather basic demographic information to make sure the two groups are similar in makeup (age, gender, activity level, comorbidities), and we will perform statistical analyses to control for potential confounding.

Evaluation

To evaluate the success of the Community Health Coach intervention, we will assess changes the primary behavioral outcome of interest: the performance of regular physical activity and the reduction of sedentary behavior. To assess changes in physical activity, the intervention will employ two main measures: daily step count data, using a validated, low-cost accelerometer, and a daily activity log, where participants will manually record their physical activity.

Participants will be given three-axis accelerometers – activity monitors – to track their daily physical activity. Accelerometers have been shown to be a validated, reliable method for physical activity assessment in studies similar to our proposed intervention, and are preferred over pedometers because they can better capture lateral movement in activities such as housework, which our target populations frequently perform.^{39,53} Activity monitors will be synced twice a month at the support group meetings; facilitators will provide a computer and will assist with syncing and uploading the data, taking care to support those participants who are not computer-literate. Low-cost activity monitors will be used to prevent any incentive to sell the tracker for cash. Individuals' daily activity data, as well as hour-by-hour activity tracking, will be monitored through an online dashboard accessible to the study investigators to determine if individuals are meeting the

desired behavioral outcome of regular physical activity.

To supplement the accelerometer data, participants will self-report their physical activity and complete daily activity logs. Activity logs, because they are done in real time, have been shown to be less susceptible to recall bias and to reduce errors investigators may encounter when using questionnaires.⁵³ For one week out of every month, participants will track their daily activity (type, duration, and frequency) in a pocket-sized log notebook. This self-report data will be compared against activity monitor data to determine the best assessment of progress toward the behavioral outcome. The log will also serve as a backup should study participants forget to wear their tracker. Logs will be turned in once per month at the support group meeting. One week per month of logging is meant to reduce the burden on participants. Physical activity assessments will be conducted throughout the year of study.

In addition to our two main assessments evaluating changes in sedentary behavior and physical activity, we will conduct a number of secondary outcome measures. One, we will employ a simple step test to measure cardiovascular fitness. Step tests are already used in South Africa to evaluate levels of physical fitness: SANHANES (the South African National Health and Nutrition Examination Survey) presently uses a three-minute simple submaximal exercise step test in their national survey.² The test involves an aerobic step box (30 centimeters high) and a timer; participants are asked to step up to and off of the box for three minutes, one foot at a time, at a steady pace established by verbal instructor from the test administrator. Upon completion of the three-minute test,

the participant's heart rate is measured, to determinate the level of fitness based on age and sex guidelines established by the Canadian Public Health Association Project.² This simple test will be conducted at baseline, at 6 months, and at the conclusion of the study at one year.

We will also evaluate secondary outcome measures by assessing changes in clinical measures, including BMI and waist circumference (WC), to evaluate the severity of overweight or obesity. Study participants will be weighed and measured (height and WC) by study staff to calculate BMI and WC at baseline, at 6 months, and at the conclusion of the study at one year. Only three measurements will be recorded to reduce the burden on the participant. The goal is to assess changes in the percent of participants with BMI and WC measures at the obese and morbidly obese levels, as well as individual changes in BMI and WC. While we do not expect to see large changes in these measures over the study period – we expect these changes to be longer-term outcomes – we still collect BMI and WC data to assess potential changes in body composition associated with the intervention.

Other clinical measures to track over the course of the study include HbA1c levels, to assess changes in diabetes control, and blood pressure, to assess management of hypertension. HbA1c and blood pressure levels for each participant will be measured at baseline, at 6 months, and at the conclusion of the study at one year (during the same time height and weight measurements are taken). Changes in HbA1c levels measure how well a patient is controlling her diabetes; the measure can tell a clinician (and the patient) how well she has

controlled her blood glucose in the past 2-3 months. A score of 7-8 is considered well-controlled, while lower scores are optimal. If a patient's score increased over the period of assessment, for example from 8 to 9 for example, that would indicate worsening diabetes control, and would be a red flag for potential complications.

HbA1c requires a blood draw during each collection, which could pose a barrier to participation; however, we will fully outline the blood draw requirement during recruitment and will explain to participants the procedure (and get their permission) in advance of enrolling them in the study.

These measures are well-established in the literature as reasonable measures for assessing changes in diabetes and hypertension. There are other clinical measures to assess diabetes management, however in a resource-poor setting such as Khayelitsha, we will limit our secondary outcome measures to a step test, BMI, WC, HbA1c, and blood pressure levels.

To evaluate psychosocial changes, specifically changes in self-efficacy as a result of the intervention, as well as a secondary outcome of the intervention, dietary changes, all participants will complete four surveys: two at baseline and two at the completion of the study at one year. We will use the Exercise Confidence Survey and the Eating Habits Confidence Survey developed by James Sallis and colleagues, which are well-established as measures of self-efficacy for exercise and diet, to assess changes in physical activity and dietary patterns resulting from participation in the intervention.⁵⁴ Prior to distribution, the surveys will be translated into Xhosa and will culturally adapted for our target

population; for example, questions on diet will include food items common in the South African diet. Study staff will assess changes in responses in the pre- and post-surveys at the individual level and at the aggregate level to measures changes in self-efficacy around physical activity and diet.

Qualitative methods will also be employed to evaluate psychosocial changes. At the conclusion of the study at one year, focus groups will be held in conjunction with the final support group meetings. Focus groups and in-depth interviews will be led by study staff and will seek to elucidate participants' feelings about barriers to regular physical activity, knowledge around types of exercise and healthy eating habits, changes in social and cultural norms, and other mediators. All focus groups will be transcribed and coded by study staff. Key themes will be identified and findings will be compared with survey responses to assess changes.

Should additional funding be available, a longer-term follow up measure of health outcomes is desirable. With sufficient resources, BMI, WC, cardiovascular fitness, blood pressure, and HbA1c levels would be assessed again at two years post-intervention and again at five years, to see if changes were maintained after the conclusion of the intervention and over time.

Behavioral, psychosocial, and clinical data will be compared between the intervention group and the control group to assess changes in the desired health outcomes and any differences between the two study groups, in order to evaluate efficacy of this intervention model in improving chronic disease self-management in a low-resource setting.

STRENGTHS AND LIMITATIONS

This study takes an intervention implementation approach, building upon qualitative findings from previous research and seeking to address barriers to physical activity and promote facilitators that help reduce sedentary behavior amongst older women in low-resource settings. The study's prospective cohort design will allow us to make comparisons between the intervention and control groups and make conclusions about the effectiveness of the Community Health Coach intervention in promoting successful chronic disease management. Our intervention aims to address both psychological changes with regard to self-efficacy, and behavior changes, with regard to physical activity, sedentary behavior, and diet, and we assess these changes using robust clinical measures, surveys, and qualitative methods. The intervention is rooted in behavioral theory and draws upon best practices drawn from the body of literature on both diabetes and hypertension management as well as HIV.

One limitation in our study is this is not a randomized control trial; future study should randomize groups of participants into the intervention or control groups to reduce potential bias. Another limitation is the shorter follow-up time: ideally, a longer follow-up would be conducted to assess whether short-term behavioral changes and health outcomes are sustained in the long run. Also, our intervention does not address environmental determinants of health and does not seek to affect attitudes and beliefs about a healthy body weight at broader community level. By only intervening at individual and interpersonal levels of socio-ecological model, the impact of our results will only be at that level.

CONCLUSIONS

While some experts argue that nutrition and diet-based interventions may be more important and effective interventions in addressing obesity-related chronic disease than those specifically targeting physical activity, we believe that there is great value in intervening upon sedentary behavior and physical activity.¹⁸ Through the promotion of physical activity and improved self-efficacy about one's ability to perform exercise, our intervention may build self-efficacy for the self-management of other healthy behaviors as well. As women in our intervention feel more in control of their ability to be physically active to help address their diabetes and/or hypertension, they may too feel more empowered to take steps to change their behavior around diet, medication adherence, and other self-management practices. By increasing women's self-efficacy to exercise, interventions like ours may have multiplying effects and result in improved self-management across myriad chronic diseases.

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Appendices

- a. Interview and Focus Group Guide
- b. IRB Approval

Interview and Focus Group Guide

CONSENT

(consent to be given verbally in Xhosa, by translator, prior to beginning or interview or focus group)

I am doing research about chronic illness and high blood and high sugar in South Africa. I'd like to talk with you about your experience with it, and if it's ok, I'd like to record our conversations and take notes. Is that ok with you?

Before we begin, there are a few important things that I need to go over with you. First, your participation is completely *voluntary*. If you decide not to participate, it will not affect you in any way. If there is any question you would rather not answer, just tell me and I will skip it.

Most interviews or focus groups take about 45 minutes, or as long as you have. *You can stop the interview or focus group at any time*, or we can reschedule the remainder for another time.

Protecting your privacy is extremely important to me -- our conversation will be kept completely *confidential*. I will not use your name in any of my research – everything will be anonymized.

Do you have any questions or concerns?

QUESTIONS

- **General Diabetes/Hypertension and Health Literacy**

******What do you know about high sugar and high blood? Please tell me what you know about it and how it impacts your life. Have they changed your life in any way?

******How did you first learn about high blood/high sugar? Who taught you about it?

******How did you get diagnosed with high blood/high sugar? Who diagnosed you and when? Were you ever told you had pre-diabetes?

*Probe: What types of tests did the doctor or nurse do? Did you see a special doctor?

******What do you think led to you getting high blood/high sugar?

******What would you tell your children or grandchildren to do in order to not get high blood/high sugar?

****What do you think can improve your health?**

***Probe:** Are you trying to do any of these things now? What barriers do you face in doing them?

****Do you feel empowered to manage your health?**

Probe: If so, how empowered do you feel to manage your chronic disease? What empowers you?

- **Physical Activity**

**** What are South African ways for women to exercise? Are these different for men and women?**

****How did you exercise when you were a girl and when you were younger? How do you exercise now?**

****How do you like to be active? Is there someone you like to be physically active with? What activities do you do together?**

****What are reasons that you might not exercise?**

- **Diet**

****What types of South African foods are healthy foods? What foods do you consider to be healthy?**

***Probe:** Are there traditional South African foods that are healthy? Unhealthy?

****What healthy foods are most available?**

****What challenges do you encounter in accessing healthy foods?**

****Who are your healthy living role models? Who in Town Two is an example of being healthy? What does he or she do that makes him or her healthy?**

FOCUS-GROUP SPECIFIC QUESTIONS

- **Social Support**

****In what ways does being part of Iliso empower you?**

***Probe:** How does Iliso empower you with regard to your health?

****What elements of Iliso help you better manage your health? What is it about the group that helps you?**

****Where do you go to get support for your high blood/high sugar? Who supports you? Who do you talk to about it the most?**

***Probe: Spouse? Family? Friends? Who plays the most important role in supporting you with your high blood/high sugar?**

****Who can you trust in Town Two? Who in your family and social circle do you trust the most to discuss your health issues?**

****Is there anyone who makes it harder for you to manage your disease? Who doesn't support you?**

- **Patient/Provider Relationship & Continuity of Care**

****Please describe your relationship with your health care provider. (what type of provider? Male/female? What clinic?)**

***Probe: Can you talk to him/her openly? How collaborative do you feel the relationship is? Do you work together?**

***Probe: Tell me about the doctors and nurses you see at the clinic. Do you see the same provider every time? How much time do they spend with you when you visit? How long does it take to get an appointment?**

***Probe: Tell me about the medications that you take for your high blood/high sugar. How do you feel they help improve your health?**

- **Self-Management**

****How are you currently managing your high blood/high sugar? What do you do to manage it? Is it complicated – if yes, what about it is complicated?**

***Probe: Who helps you manage it?**

****What do you feel is in your control to manage, and what do you feel is out of your control? (and thus a barrier to managing your diabetes)**

***Probe: (Example: control over your diet, exercise, doctor's visits, medication...)**

***Probe: What does successfully managing your diabetes look like to you? What do you need to be able to control it better?**

- **Stress**

**What does stress mean to you? How do you define stress?

**What aspects of your life cause you the most stress? What or who causes you to feel stressed or adds stress to your life?

**In way ways does stress affect your high blood/high sugar?

**Who helps you relieve your stress? Do you do certain activities to help you feel less stressed?

*Probe: What is something you do when you are feeling sick, to make yourself feel better?

**How does your stress affect your health? Your high blood/high sugar?

- **Behavior Change**

**What has your doctor or nurse encouraged you to do to better manage your high blood/high sugar?

Probe: What have they encouraged you to change with regard to your diet?
To physical activity?

**What have you done to change your behavior around diet and exercise?

Probe: Who or what has helped you make these changes?

Probe: What kinds of physical activity do you enjoy doing?

**What would you like to do, but haven't been able to?

Probe: Who or what is preventing you from making a change?

IAA# 17-35

IRB Authorization Agreement

Name of Institution or Organization Providing IRB Review:

University of Cape Town

IRB Registration #: IRB00001938

Federalwide Assurance (FWA) #: FWA00001637

Name of Institution Relying on the Designated IRB:

Brown University

IRB Registration #: IRB00000556

Federalwide Assurance (FWA) #: FWA00004460

The officials signing below agree that Brown University may rely on the designated IRB for review and continuing oversight of its human research limited to the following specific project:

Project Title: Experiences of living with and managing chronic illness in low-resource settings: A formative qualitative study in Khayelitsha, South Africa (UCT HREC #326/2016)

P.I: Dr. Chris Colvin (UCT) and Dr. Mark Lurie (Brown, for Brown staff/student component)

Sponsor: None

The following terms and conditions apply:

- (1) The review and continuing oversight performed by the UCT IRB will meet the human research protections requirements of the OHRP-approved FWAs of both institutions.
- (2) Brown University is responsible for ensuring compliance with the determinations of the UCT IRB and with the terms of its own OHRP-approved Assurance.
- (3) Brown University agrees that it assumes full and complete responsibility for the conduct of Brown University research that is the subject matter of this agreement and that it is familiar with and assumes complete and full responsibility for compliance with any and all applicable laws, rules, and regulations pertaining to the program of research that is the subject matter of this agreement.
- (4) University of Cape Town policies and procedures will be followed for the reporting of serious adverse events.
- (5) The UCT IRB will provide copies of all IRB approvals for the above project (including modifications, progress reports, and serious adverse event reports), to the Brown

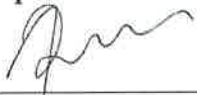


University IRB, on a timely basis, for the duration of the project. Relevant minutes of IRB meetings will be made available to Brown University upon request.

- (6) This agreement may be terminated by either Institution with thirty (30) days notice. Upon receipt of any notice of termination, no new commitments will be made and, to the extent possible, all outstanding commitments that relate to this agreement will be cancelled. Upon termination of this agreement, the provision of IRB oversight by University of Cape Town is considered to be terminated.

This document is to be kept on file at both institutions and provided to OHRP upon request.

University of Cape Town:



Marc Blockman (or designee)

Date: 2017-06-04

Brown University:



Susan Carton-Lopez
Associate Director, Human Research Protection Program

Date: 6/8/17