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Title

Guyanese expatriate women ask: “Is it a touch of sugar?”

Abstract

Eight Guyanese expatriate women, who had been living in and around London for decades, came together driven by a participatory inquiry approach. Do we just have ‘a touch of sugar’ or is diabetes a serious affliction were questions asked. The study’s objective was to find answers to these questions. Three nurse academics, one a Guyanese / English woman herself, researched alongside participants. After several years of storytelling and group discussion (2010-2015), the women recognised that when they connected socially, the practical effect of togetherness was empowerment. Researching with participants fostered new understandings of diabetes and improved self-management of this chronic condition. This was achieved through the collaborative character of the inquiry and as a practical response to the problems women were facing. They continue to engage with each other and are reaching out to the wider UK Guyanese community. They have a strong voice about living well with diabetes and strongly reject the myth that diabetes is only ‘a touch of sugar.’

Key words

Guyanese, expatriate, women, participatory action research, diabetes

Introduction

Eight women diagnosed with diabetes collaborated in a participatory action research (PAR) group. 'Is diabetes a serious affliction?' was the question asked. What is 'a touch of sugar?' The study's objective was to find answers to these questions. Three nurse academics researched alongside participants.

In an effort to set the context for this study (2010-2015) it is important to describe the geography and political climate of the country in which the women were born and raised. Guyana is the only English speaking country in South America bordered by the Atlantic Ocean on the North, Brazil on the South, Suriname on the East and Venezuela on the West. Previously known as British Guiana it gained independence from the United Kingdom (UK) in May 1966. Economic hardship, violence and turmoil between two of the dominant ethnic groups, African and Indian Guyanese led to a mass exodus of Guyanese to Britain, USA and Canada (Williams 1991, Peake and Trotz 1999). Guyana's emigration rate is among the highest in the world, 55 per cent of its citizens reside elsewhere and more than 80% of Guyanese tertiary educated nationals have emigrated (CIA website 2016). A large middle class, well-educated population left Guyana in the 1960s and 1970s to live as migrants, expatriates and/or residents in predominantly English speaking countries. We will use these terms 'migrants, expatriates and/or residents' interchangeably. Many Guyanese now reside in the United Kingdom. Facts published by Diabetes UK (May 2015), show that Type 2 diabetes is six times more common in people of South Asian descent and three times more common in people of African and African – Caribbean origin.

The study

The conversations started in 2010 when the first author, a nurse academic and Guyanese expatriate, heard from family and friends about a condition described as a 'touch of sugar.' What is it? Is it family related? Questions snowballed including some about genetic predisposition, the Guyanese diet and this group's food preferences. A study proposal was submitted to the University's Ethics Committee and approved. Participants were recruited from Guyanese organisations listed on its High Commission UK website. A poster was circulated amongst the Guyanese community and organisations in the London area. Self-selecting volunteers made contact via the university and were sent a letter, information sheet and consent form. Formal written consent was obtained from the participants prior to commencement of the study. Eight women volunteered for the study: all were born in Guyana and had been living in the UK on an average of 40 years. Their median age was 69, and demographically speaking, they were middle class, well educated and had been employed until recently as administrators, midwives, business partners and so on. All had been diagnosed with Type 2 diabetes. It was surprising to us, given the close Guyanese community in London, that prior to this study participants did not know each other.

The participatory action research (PAR) approach guiding this study follows the processes of 'looking, thinking and acting' as a systematic cyclical action (Koch & Kralik 2006; Koch 2015). This approach has been used with many groups living with a chronic illness but on this occasion we asked participants to tell us about living with diabetes and the impact this has had (or not) on their lives. Although we wanted to explore a 'touch of sugar' we waited for the participants to raise the subject. We refer to the '*looking*' process as information gathering. Resources and information about diabetes are shared during this process. *Thinking* gives the individual/group time to reflect, to make sense of what is happening and to engage in dialogue with others in the group if they so desire. These processes are interactive and cyclical as mentioned earlier. The participants drive *action* when they are ready. When '*acting*', the women consider options or choices available to them towards self-management of diabetes and other aspects of development that are termed loosely as reforms.

Principles guiding this inquiry incorporated social justice, equity, freedom of speech and human rights. This study shows that when these principles are embraced throughout the study, participants can grow and develop.

Methodologically, storytelling and the participatory group process are often used interchangeably with the study's main aim to facilitate reform. Participants are in control as they set their own agenda based on their needs, they decide on the actions to be taken. This participatory process can be mutually beneficial. In groups, participants share experiences and learn from each other. Researchers learn alongside participants. The three researchers [reflected](#) through journaling, debriefing after each 'event' and constant discussion.

Eight excerpts from their storylines: Living with diabetes

The women were asked to talk about living with diabetes and wanted to talk with researchers about their chronic condition. The first conversation took place in the women's own homes, often with two of the researchers present. Following Koch and Kralik's (2006) data generation and analysis protocol, interviews were recorded, transcribed and storylines were returned to participants for their validation, reflection and comment. Once we had met all the women and initial interviews were completed, we invited the women to join a group. It was made clear that the women would set the agenda for discussion. Group sessions were held in rotation at one participant's house. These were social events, initially with elaborate Guyanese food preparations, which became more restrained as the topic of healthy eating was placed on the group's agenda. The first author facilitated the group and held several sessions at her house, allowing the two co-researchers to Skype if they were elsewhere. Before we discuss the group process we privilege eight excerpts that introduce the women. We believe it is important to share these excerpts, describing the women's experiences being diagnosed and showing their initial understanding of diabetes so that their subsequent development and increased understandings become evident in the group process to follow. Having a voice was extremely important to the participants and we honour their words here through their storytelling capacity. Names are self-selected and fictional.

Vera

I was diagnosed with diabetes around the end of September 1983 but had been experiencing symptoms for eighteen months. Prior to diagnosis I had experienced many symptoms and reported these to my General Practitioner (GP), but no tests were done. In the end it was one of my staff at work picked up on my condition. She had been a diabetic for a long time. Then I had month's wait before an appointment to hospital for tests. I was then diagnosed with Type 2 diabetes. I had much to learn. I monitored my medications and noticed that tablets combined with the diet were not working. I reported this to the GP and was started on insulin. Then my eyes started to give me trouble. When medical staff looked at my eyes they talked between themselves. They did not talk to me but over my head. Without explanation they 'lasered' my eyes. I said to my family 'this cannot be right.' So I saw somebody privately and when he looked at my eyes he said that I could go blind at any minute! To date my medical management has been haphazard.

My father must have been in his late 30s when he developed what we refer to in the Caribbean as 'a touch of sugar.' I know two people from the Caribbean and these are highly intelligent professional people, well I think can't you work this one out for yourself, if somebody told you have 'a touch of sugar', you're either prone to diabetes or you've actually got it. My father may have had it. When I look back I think I was always prone to diabetes. From an early age I used to get heavy-headed and my skin had hives, what we call 'mad blood.' I get it even now if I eat anything that is too sweet.

'A touch of sugar' was raised in this first interview, Vera points out that trivialising this serious condition can have health consequences. Vera was not diagnosed in a timely manner. Not

receiving a diagnosis made her feel powerless. Health care practitioners, she asserted, ignored warning signs.

Not only Vera but also other participants said that they knew something was wrong and kept asking health care staff for an explanation of their symptoms. Health care practitioners were not responsive. As we know, an early diagnosis is crucial when an individual has Type 2 diabetes. It enables them to commence their journey of self-management (Odette et al 2004). Unfortunately this was delayed for a majority of our participants. They wanted a diagnosis confirmed before they felt confident in making lifestyle changes.

Marjorie

My diabetes was first diagnosed at Easter time 1999. For about six months, I thought I had this thing because I would drink a two-litre bottle of coke in half a day. When I first noticed something was wrong I was just getting fatter and partying at all the Guyanese scenes. I ate all the Guyanese food, crisps and biscuits.

I was at work on Holy Thursday that year and suddenly I went blind. I shouted to my boss Paul: "Paul I can't see!" He called a cab and phoned the doctors to make an emergency appointment. I was shocked with this diagnosis of diabetes. The doctor gave me a prescription of Metformin for some medication. I was under a medical team at a diabetic clinic at a major local hospital for a while. Then I was warned: "if you are not good at controlling your diabetes, you might have to inject insulin." A niece who lives in Barbados has diabetes.

As Guyanese living in England we tend to stick together. I have noticed that Guyanese who have diabetes do not seem to follow a strict diet. They eat a lot of sugary foods like 'sugar cake,' sugar cane juice. I think they could be in denial.

Like Vera, Marjorie should not have been surprised at the genetic predisposition to diabetes, as they knew many Guyanese diagnosed with 'sugar.' Other factors like obesity and hypertension were also significant predictors. Marjorie points to a lifestyle of eating carbohydrate rich foods, putting on weight, yet was shocked when she received her diagnosis.

Interviews revealed that although women had been diagnosed many years ago, their information about diabetes was not current. Only one person (Pam) had been given educational resources. Others had access to computers and could search an evidenced based site on the Internet to update their knowledge on latest developments in diabetes treatment and management, but it had not occurred to them to do so. Health care practitioners had neglected this group, perhaps assuming that those diagnosed so many years ago were in control of self-management. They came to the study with stories about poor quality of doctor/patient relationship and about the coercion used to ensure conformity to the bio-medically driven treatment regimes, and about the failure of health care practitioners to perceive their problems from their perspective and the disregard of their own experiences in relation to management of their diabetes. As a result of the group discussion the women realised that they had required more medical / health attention and proceeded to navigate for appropriate services, hoping that those sought would be responsive.

Pam

My diabetes was first diagnosed in October 2006. Getting diabetes was something extra that came along as I already self-managed fibromyalgia and arthritis. I manage my diabetes with assistance from the diabetic nurse with whom I meet every six weeks. Before 2007 my blood pressure was high but I did not want to take any more tablets so I said to the nurse "I'll bring it down." I regularly check my glucose levels with testers. But coming back to the diabetes, I'm not really worried about it because my mother had

it when she was in her fifties and she always managed it with diet. She lived with it for a very long time. Six of my sisters have diabetes.

I'm a Buddhist and we have a great faith that the body can heal itself. I try to have a lot of leafy green vegetables and water based fruit because that is what the body needs, more water. I know I can take care of myself. One of the best things I attended back in 2006 was a six-week diabetic course. I was given a book on diabetes management and the course was really instrumental in helping me to identify the foods that I could eat.

I am influenced by my upbringing in Guyana, where we ate very well. We regularly took medicines like Scots emulsion, cod liver oil, cascara or castor oil, senna pods and everything, and we ate vegetables, fish and meat. I have a lot of support from Guyanese friends with whom I talk regularly. When I visited Guyana I noticed that people with diabetes did not seem to be strict with their diet. Instead they eat lots of sweet things. They think it is just 'a touch of sugar.'

Being diagnosed later than the other participants meant that services such as diabetes classes were made available, and by Pam's account, Health care practitioners appeared to be responsive. Given Pam had exposure to diabetic classes and information she still had many unanswered question about her management. Nevertheless the National Health Service (NHS) has claimed to make improvements in its diabetes service delivery in the last few years (Diabetes UK web site).

This excerpt shows that our participants travel frequently to other English language destinations such as Canada, Australia and USA, gathering with Guyanese friends that live elsewhere. Visiting family back home to Guyana is part of the travel routine. When women return from travel to Guyana they report that diabetes is a major health problem 'back home.' There is always another family member who has 'a touch of sugar.' Participants questioned whether this chronic illness is genetically predetermined. This question arose from them being diagnosed as well as many family members.

Bea

My diabetes was first diagnosed twenty years ago in 1990. I come from a family of known diabetics. One of the first symptoms experienced was when I came home from work I would feel a bit dizzy. It was totally out of the blue one day the GP told me to come to the surgery and I had the fasting glucose test done. Only then did he inform me that I was diabetic. Yes, sometimes people do exhibit symptoms such as feeling very thirsty but I can't remember feeling like that. Once diagnosed I self-managed with diet. Later I took a drug called metformin. Then there was a problem with my kidneys. Eventually my GP took heed and had me investigated. I am now on insulin.

You need to be careful with the diet when you are a diabetic. Several Guyanese friends have tried alternative treatments and herbal remedies and I am tempted to try some. My Buddhist faith also helps me come to terms with my diabetes. I find this comforting. I worry about my family getting diabetes. I know I have a family history and how little had been understood or done for my mother and father. My mother remained undiagnosed until 'the end' whereas my father refused treatment because he thought it was just 'a touch of sugar.'

This is another story where the person has not been listened to by health care practitioners and diagnosis was made much too late for prevention of complications. 'A touch of sugar' is the constant refrain.

Jane

In mid-April 1973, I came to England with my son who was 14. I have lived here in this house since August 1980. Now that I am retired and 71 years old, I still lead an active life. I get support from my family and friends. I am a very active person in the Guyanese community.

I was diagnosed with diabetes about ten years ago after I retired from my position at a department store. I did not have any symptoms but was aware that my father and grandparents had died from this condition so I took preventive action by checking regularly from the day I came to England to see if I had acquired it. I was aware people in Guyana talked about 'a touch of sugar.' After I was diagnosed I was on a diet only for the first three years and then tablets. During the early stages of the condition, my glucose levels were perfect in the daytime but when I went to sleep and woke up in the mornings, my sugar levels were always high and that is the case up to now. I was sweating a lot during the night because I hadn't eaten all night and the consultant believed that I was having a hypoglycaemic coma. The consultant suggested that I eat a slice of bread before going to bed and the sweating eventually stopped. About two years ago I was started on insulin. I take insulin once a day at night.

Family reportedly had 'a touch of sugar.' Again it is the constant catch phrase.

Shirley

I was diagnosed in 1998. I just wasn't feeling right. I saw the doctor several times but she didn't know what was wrong. She put it down to stress. In the end I was diagnosed with diabetes. I have been on tablets since then, Metformin, which I am on until now. I had to change my eating habits, as I never liked to eat regularly. I ate erratically, so I was forced to eat properly and at the correct time. Coming back to the management of diabetes and food, I never liked sweet things. Sweet things do not have anything to do with diabetes, it is another myth but Guyanese eat a lot of sugary foods. I don't like cooking. It is not my strong point. Someone said you can't come from Guyana and don't like to cook. I said: 'I am sure not all Guyanese like cooking.'

Delay in being diagnosed is not unusual as we heard from Shirley and Vera. We ponder whether it is more likely that women of colour are not heard in the NHS system. Women talked about racism and discrimination in one to one conversations but did not want to pursue this as a group. Possible reasons why women were ignored and diagnosis delayed did not reach the group agenda.

Agnes

I was born in Georgetown but grew up in New Amsterdam and finished my schooling there. The reason for coming to England was to join my husband. I used to work at a Housing Benefit office for almost 20 years. I retired nearly four years ago. I don't know now what is happening with diabetes in Guyana today but Guyanese eat loads of sugar. I don't think they are aware that they could get diabetes.

I was diagnosed with diabetes in 2007. I noticed that I had a problem when I got up in the morning. I would feel dizzy and have blurred vision so I decided to make an appointment with the GP. I was prescribed Metformin and asked to attend diabetic classes. I have been going regularly to the clinic, where they test my blood sugar to see if the level has increased. My husband and son used herbal remedies to treat their diabetes. I just use the medication.

I brought my husband home from Guyana. He was mugged when he was there on holidays. Then he had a stroke and passed away. We had a coroner's inquest that brought some closure, but when I came home that afternoon after the hearing, I almost

fainted. My son said: 'mum you need to go and rest.' I was admitted to hospital about three weeks ago. I heard them saying that I had a problem with my heart.

Being stressed is often given as a reason for triggering diabetes or a hypoglycaemic event. The question of stress as a trigger was put on the agenda for discussion in the group. In all stories, Guyana comes up in conversation, being Guyanese is an important consideration for identity, food choices and queries about genetic predisposition.

Jillian

I was diagnosed with Type 2 diabetes in 2002 following a visit to my husband's brother in Guyana. His wife noticed that I was losing weight. My husband's brother, who is also a diabetic, gave me a blood test using his equipment. My blood sugar reading was 14. It had not occurred to me that I had diabetes as I did not have the usual symptoms like being thirsty or anything like that. But I have a family history of diabetes. Both of my parents were diabetic. My mother died from kidney failure. She used to be on insulin but my father lived to a good old age. I have a sister (a nun) who is diabetic and my daughter was diagnosed at university when she was in her early twenties. Guyanese people talk a lot about 'a touch of sugar' and don't realise how serious diabetes is.

My diet consists partly of Guyanese foods. I don't cook every day. I just eat what I feel like, chicken, meatballs or soup.

We arrived in England in November 1964 and it was so cold. I just wanted to go back to Guyana. Unfortunately we had to return to Guyana in 1971 as my husband became Chief of Protocol. We came back permanently in 1985 and I have been here ever since. We had been married for 51 years when he died from dementia. When he became ill I used to give him his insulin because he had diabetes too. He managed it well until he got the dementia. My husband passed away in February this year.

It is obvious that diabetes has invaded the lives of all participants including their close family members and friends, both in England and in Guyana. Some of the women felt they had a greater propensity to develop diabetes due to family history as many of their relatives: siblings, parents, spouses, grandparents and children had the condition. In fact six women had close relatives living with diabetes yet they were surprised when they were diagnosed. Even with a family history, certain factors potentially increased the women's risk of diabetes such as age, being overweight, having hypertension and abnormal lipid levels. Specific studies (Lindstrom and Tuomilehto 2003; Talmud et al 2010) have focused on genetic models/tools to predict the risk of Type 2 Diabetes, which concluded that parental history and other factors such as obesity, hypertension remained significant predictors (Diabetes UK 2008, Tillin et al 2012). As we continued talking in the group, these questions came to the fore.

Cultural implications: a 'touch of sugar'

We relied on interview conversations and group discussions. In the group, conversational exchange between the women to some extent duplicated the stories we had been told in the interview situation. Prior to meeting as a group a few women had ignored managing their diabetes but were now discovering through group information exchange that this could have serious consequences and started to take action. Life style changes as they are euphemistically called were taken seriously usually meaning the women increased exercise, read food labels, started eating healthily and became better informed about food preparation and practices.

'A touch of sugar' was an often-used expression originally thought by the women to have minimal health consequences. Vera spoke quite fondly about her father having 'a touch of sugar' but as we continued talking she realised that he might have had diabetes. Marjorie said Guyanese people did not seem to be as strict with their diet because they thought they only had 'a touch of sugar'. Having diabetes when described as 'a touch of sugar' implies that diabetes

is not taken seriously (Clark and Clark 1998, Phillips 2006). In subsequent group conversations Shirley said quite strongly: 'people are in denial'. Eventually the group strongly argued that having 'a touch of sugar' be rejected as a dangerous perception and advocated not using this expression whenever it arose as part of consciousness raising within the Guyanese community.

Food, food and food

Participants asked whether their diabetes was related to eating comfort foods from their country of origin. The ethnicity of Guyanese people is a melting pot of British, Indian, African, Amerindian, Chinese, Mixed and Portuguese (Back et al 2012). Foods encapsulate centuries of invasion, migration and slavery and like other Anglo Caribbean countries food products consumed reflect its colonial history and tropical climate (Smock 2008). In the group the women had heated discussion about the types of food and their origins. The Amerindians taught them to prepare cassava bread, atchee and pepperpot. The Africans introduced metagee/mettem, konkee and peas with rice. We heard that Creole dishes use fresh coconut oil for cooking and its cuisine specialises in salt fish and black pudding. Indians cook dhal, curries and roti. The Chinese have chow-mien and lo mien to add to the mix. The Portuguese are famous for their black cake and garlic pork (Smock 2008). Food continued to be on their agenda for discussion throughout the study. Cassava, root vegetables, green peppers, onions and celery are prepared in many different ways often with large amount of cereals. Creole dishes incorporated spicy sauces, fried meats and seafood. Desserts were very sweet and rich in flavour due to the use of sugar and rum. The women talked extensively about these foods and making dietary changes was a huge challenge. They developed knowledge and understanding that the Guyanese diet was not necessarily appropriate, as they needed to consume a healthy diet. Numerous conversations followed about what constitutes healthy eating.

Group Learning

As the group sessions continued, we collaborated to access relevant information about Type 2 diabetes. The women appeared to be hungry for knowledge. After years of ignoring and/or not managing they realised, as a group, there was much to know. We used diabetes journals; Google on the Internet and invited a Diabetes Specialist Nurse to two of the group's PAR sessions. Many questions were asked of the Diabetes Specialist Nurse about the use of alternative herbal therapies, healthy eating and blood sugar measurements.

The women attributed mood changes or 'feeling low' to the effects of living with diabetes. Several women believed that stress had negatively influenced their diabetic state and some women even suggested that stress had contributed to them becoming a diabetic. In the group the women confided shared feelings of depression, stress and anxiety, but agreed that since joining the group their emotional health had improved.

Initially the women were not fully cognisant of the complications of diabetes, especially hypoglycaemia, or the impact these were having on their bodies. In the course of that first year in meeting together the women made significant life changes. Listening and supporting each other were crucial actions. Each session they reported to each other what had been achieved: exercise, review of their diet, the foods acquired for healthy eating and blood testing. They became more assertive in demanding health checks from their GP. Actions were being taken.

Connecting with others in the group sessions assisted the women in managing their lifestyle challenges to consider healthy eating and taking more exercise. Kolb's (1984) experiential learning cycle captures the collaborative learning that developed among the women. Kolb's learning cycle may further explain the learning that had taken place among the women in the group. In addition to cycles of 'look, think and act' (Koch and Kralik 2006) adopted for this PAR approach, Kolb's four-staged model provided a structure that provides theoretical strength to the process of learning and taking action.

Kolb (1984) argues that individuals are more likely to learn when it is an active process, as we add to what we know and believe already; however we need to be fully involved in this learning

process as we make sense of what is happening in the world. The women needed to make sense of living with their diabetes as they shared their experiences with each other in the group sessions. These facilitated group sessions encouraged their exchange of ideas and experiences as a social process of constructing a shared understanding of their long-term condition and actions taken to improve it. Whilst we facilitated the group conversations by encouraging questions, prompting reflection and suggesting alternate ways of thinking, the women reviewed their current practices in managing their diabetes whilst learning at their own pace, reflecting on their own experiences and understandings, and applying the learning gained into practical situations. The learning cycle acted as a focus for action and evaluation of learning. This is the cyclical nature of Koch and Kralik's (2006) PAR process that we believe led to acceleration of the women's learning in the group sessions, and subsequent enhancement of these women's lives. The women's learning accelerated in the group sessions as they became more reflective, or dwelled longer in the 'thinking' phase of the process. Learning is continuing, as the women have stayed connected with each other.

Being Guyanese

As stated earlier, participants did not know each other prior to meeting in PAR groups. Nevertheless maintaining contact within this group of Guyanese expatriate women mattered. Opportunities to meet in the group are rarely missed. The women developed profound loyalty and found support from each other. They travelled distances to meet with each other and made multiple journeys within and outside the UK. Knowing that Guyana is a country that has more Guyanese expatriates than residents (Trotz 2006:55) suggests that these "interactions raise issues of nostalgia that sentimentalizes memory among the diaspora of Guyanese but in ways that obscured the complex and uneven practices through which identifications with Guyana and with others 'like us' are made". Trotz (2006:56) further questions whether "we need to consider the kinds of imaginative geographies that are called on by those who do not regularly return to their homeland" but feel the need to maintain links regularly with those from the diaspora. Further research is needed to explore our understanding of the social networks that sustain people across time and place including the availability and usage of technology driven social media.

It was not unusual for the women to talk about 'being Guyanese'. As Trotz (2006) signalled earlier, women spoke of their homeland in glowing terms as if Guyana is still as they left it many years ago. The country left behind was viewed through rose coloured glasses. Their middle class background was tied to privileges such as having servants, gardeners and cooks. Making a transition to a cold climate without those privileges was difficult. Comparisons with living in the UK were unfavourable. As discussed, the women were constant travellers. Including their migratory experience they had made multiple journeys within the UK and overseas to reconnect with Guyanese family, friends or attend school reunions. We believe this is a unique characteristic of Guyanese who create space and time to reconnect and can financially afford to do so.

Food and identity were intimately tied together. Their preoccupation with Guyanese food depicts their cultural heritage and was associated with comfort. They talked frequently about Chinese foods or spices used in Indian curries, peas and rice and root vegetables such as cassava, plantains and sweet potatoes were their favourites. These Guyanese loved to eat and they loved their food. Changing their lifestyle and diet appeared to be the biggest challenge.

The PAR group sessions gave the women the opportunity to meet with a like-minded group of individuals who had faced discrimination, racism and other obstacles in the UK but had survived. We feel that women belonging to the same cultural group with common beliefs and values can be beneficial and is a good explanation why the group has worked for these Guyanese / English women.

Eight women and three co-researchers continue to meet and/or talk (Skype) about actions they have taken to improve their lives. This study is remarkable in that long after the study's final report was written (PhD was awarded in 2015), the women thrive in an ongoing relationship that nurtures their cultural cohesion and we argue, has significantly improved their day-to-day self-management of diabetes.

The first author maintained a reflective journal throughout the inquiry. She queried if her role as a woman / researcher / facilitator / registered nurse / Guyanese expatriate / UK citizen was influencing and /or working as a change agent. Her critical stance shifted noticeably. For instance, the first author initially took for granted her Guyanese background and identity. Right from the start, from the perspective of authors two and three, the way in which women embraced each other culturally in order to learn collaboratively was exceptional. Nevertheless it took a few years of critical reflection before the first author was able to see that all her identities had impacted on the study. Finally, she reignited one of her identities to be proudly Guyanese. Arriving in the UK in the 1970s, and living an English life, she has reconnected with London's Guyanese community. She is now motivated to instigate further Guyanese group studies in the UK and in Guyana.

Conclusion

What does this mean for diabetes?

In answer to the questions posed at the outset, the group campaigns strongly that 'a touch of sugar' is a dangerous myth. Diabetes, they contend, is a serious affliction and warrants ongoing education. Confidence towards managing self-care can be built collaboratively in a group of like-minded individuals, particularly if they share a cultural past.

What does this mean for the group?

Researching with this group of women has promoted new understandings of diabetes, improved self-management and that this was achieved through the group's cultural cohesion. The women learnt that self-management is not a constant process but may fluctuate as life and illness itself present new challenges. Through storytelling and group discussion, participants recognised that when they connected socially, the practical effect of togetherness was empowerment. Identity was thought to be a dynamic process in this group as they embodied multiple identities. These shifted and change depending on the learning and social contexts but being Guyanese was one of the strongest identities that connected them. Group cohesion and working together to improve lives are important findings.

What does this mean for action research?

The Action Research (AR) family is large and we acknowledge that we have selected just one approach for our inquiry. This study demonstrates how inquiries using PAR principles can and do make a difference in the health care context. As participants had set the agenda, made plans and explored resources collaboratively, their voices have been privileged. Outcomes show that the women have taken action towards a positive impact. We have demonstrated that the PAR process is conducive to learning and the Guyanese cultural context cemented these relationships in a way not seen in previous research work.

Group dynamics are always fascinating but the women's attentiveness in listening to each other, the joy in having a voice for the very first time and being acknowledged as a person who mattered was liberating. Today participants are part of wider UK Guyanese community. The women have a strong voice about living well with diabetes and reject the myth that diabetes is only 'a touch of sugar.' This is their message to the wider community.

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