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- 12 Caribbean “substitution culture” is a barrier to effective treatment of persons with diabetic foot infections  
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## Caribbean “substitution culture” is a barrier to effective treatment of persons with diabetic foot infections

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### Abstract

Diabetes-related amputation rates are high in the Caribbean. Many authorities have identified independent risk factors for diabetes-related amputations, but cultural factors remain underappreciated. We coined the term “Caribbean substitution culture” to describe the attitude of patients with diabetic foot infections in which they refuse to access medical care, instead voluntarily choosing to substitute “bush medicines” or other alternative therapies in the place of conventional treatment. Recognizing that the Caribbean substitution culture is a barrier to effective treatment of diabetic foot infections is the first step in curbing these practices. In this paper, we discuss the issues related to the Caribbean substitution culture, including the demographics of the population at risk, the alternative therapeutic practices and potential public health strategies to combat this practice.

**Key words:** Diabetes; Surgery; Infection; Caribbean; Foot

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**Core tip:** Many authorities have identified independent risk factors for diabetes-related amputations, but cultural factors remain underappreciated. We coined the term “Caribbean Substitution Culture” to describe the attitude of patients with diabetic foot infections in which they refuse to access medical care, instead voluntarily choosing to substitute “bush medicines” or other alternative therapies in the place of conventional treatment. We discuss the issues related to the Caribbean Substitution Culture, including the demographics of the population at risk, the alternative therapeutic practices and potential public health strategies to combat this practice.

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## INTRODUCTION

In the Caribbean, persons with diabetes have 0.75% annual risk to develop foot infections<sup>[1]</sup>. Diabetic foot infections rank high among the admission diagnoses in Caribbean hospitals<sup>[2-6]</sup>. These patients consume significant human and financial resources. The economic burden is illustrated by a report that one Caribbean country spent \$85 million United States dollars in just one year solely to treat patients hospitalized with diabetic foot infections<sup>[1]</sup> – an underestimate since that figure excluded outpatient treatments and treatments in private facilities.

Ideally, we aim to prevent persons with diabetes from developing foot infections. To achieve this, there are many evidence-based recommendations for prevention that are tailored to the needs of the region<sup>[2-9]</sup>. If these patients do develop foot infections, however, five therapeutic goals should be observed: (1) Achieve glycemic control; (2) Control local infection; (3) Prevent systemic sequelae of sepsis; (4) Prevent amputations; and (5) Preserve life. Despite evidence-based therapeutic guidelines specific to the Caribbean environment<sup>[2,3,5,8-12]</sup>, there are still poor clinical outcomes across the region. Since limb salvage is one of the therapeutic goals, we can consider lower limb amputations as a proxy for therapeutic failure. In the Caribbean, the reported annual incidence of lower limb amputations in persons with diabetes ranges from as low as 54 per 100000 persons per year in Trinidad & Tobago<sup>[2]</sup> to as high as 936 per 100000 persons per year in Barbados<sup>[9]</sup> – ranking among the highest in the world<sup>[9]</sup>.

## DEFINITION OF THE PROBLEM

Many authorities have attempted to determine the reason such poor outcomes exist in the Caribbean. They have identified several independent risk factors for diabetes-related amputations, including: Low socioeconomic status<sup>[13]</sup>, inadequate footwear<sup>[5-9]</sup>, improper nail care<sup>[5,6]</sup>, poor diabetes control<sup>[6,9,14]</sup>, sensory neuropathy<sup>[7,9,15]</sup>, peripheral arterial occlusive disease<sup>[9,15]</sup>, previous ulceration<sup>[14,15]</sup>, late clinical presentation<sup>[3,6,12,14]</sup>, delayed medical intervention<sup>[3,8]</sup> and infection with resistant microbes<sup>[11]</sup>. But the Caribbean “substitution culture” is a risk factor that is underappreciated. This is where patients with diabetic foot infections refuse to access medical care, instead voluntarily choosing to “watch it” while substituting “bush medicines” or other alternative therapies in the place of conventional treatment. These alternative therapies are regimens that are not used in conventional medicine, for which there is a paucity of data on safety, efficacy and effectiveness<sup>[16]</sup>. Most doctors practicing in the Caribbean have encountered variations of the substitution culture, but scientific literature has paid little attention to this practice.

There are many forms of alternative therapies used in the substitution culture. The commonest method encountered is to apply topical “medicinal” agents to wounds that are then enclosed in improvised, and often unsterile, dressings. A variety of substances are used, but the most common is paraffin wax heated over a flame and poured directly onto open wounds<sup>[17]</sup>. In persons with diabetes who have neuropathy, this could result in devastating thermal injury. In order of frequency, other agents encountered include honey, wonder of world (*Kalanchoe Pinnata*) leaves<sup>[18]</sup>, ichthammol ointment, aloe vera, hot oil (may cause direct injury), hot cooking grease (may cause direct injury), vaseline, iodex, epsom salts, methylated spirits, black salve, hydrogen peroxide and green papaya. In our experience, we have found that there is no standardized agent, dosing, frequency of application or duration of therapy.

Oral agents are also used, with bush teas being the most common. These are prepared by boiling water with a variety of ingredients including: leaves from cerasee (*Momordica charantia*), fever grass (*Cymbopogon*), noni (*Morinda citrifolia*), guinea hen weed (*Petiveria alliacea*), periwinkle (*Catharanthus roseus*), soursop (*Annona muricata*), arrowroot (*Maranta arundinacea*), black mint (*Tagetes minuta*), ganga (*Cannabis sativa*), aloe vera, lime (*Citrus aurantifolia*), milk thistle (*Silymarin*) and dandelion (*Taraxacum*). Other parts of vegetation are also used, such as the root of

ginger (*Zingiber officinale*), vines or bark from guaco (*Mikania guaco*), bark or fruit from annatto (*Bixa orellana*), coconut shell (*Cocos nucifera*) and cashew bark (*Anacardium occidentale*).

An uncommon but disturbing practice uncovered in some Caribbean countries is for persons to consume “left over tablets prescribed for other persons” to treat other diseases<sup>[14]</sup>. But even more disturbing is the practice of purchasing “pills” from streetside vendors<sup>[14]</sup>. These are dangerous practices because there is no instruction on the dose, frequency or duration of the drugs. And, in the latter case, persons were not even aware of the drug they were taking. Technically, these were not alternative therapies because conventional medicines were used<sup>[16]</sup>, but they were delivered in a reckless manner. This demonstrates the popularity of the substitution culture.

We performed a literature review to determine whether similar practices existed in other countries. We encountered reports from India<sup>[19,20]</sup>, Bangladesh<sup>[21,22]</sup>, China<sup>[23-27]</sup>, Malaysia<sup>[28]</sup>, Iran<sup>[29,30]</sup>, Turkey<sup>[31]</sup> and the African continent<sup>[32-35]</sup> in which persons with diabetes used non-medical remedies attempting to control their glucose levels. Few reports detailed persons with diabetes using alternative strategies specifically to treat foot infections<sup>[17,18,36-38]</sup> and none demonstrated any benefit derived from the use of these remedies.

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## SCOPE OF THE PROBLEM

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The reason the substitution culture is so prominent in the Caribbean remains uncertain, but we believe that it is a wider societal issue where there is an ingrained reverence for traditional healers, a low perceived value of conventional medical therapy, an under-estimation of the consequences of foot infections and an element of non-compliance. Whatever the cause, the substitution culture can undermine the primary and secondary prevention strategies that Caribbean policy makers have put in place. If the alternative therapies are not effective, it may cause patients to seek conventional care late in the disease course, only after they admit that their alternative therapies have failed. The trickle-down effect is that infections may be allowed to progress unchecked, increasing the risk of amputation, sepsis and death.

A few investigators attempted to determine the value of alternative therapies specifically with relation to the treatment of diabetic foot infections. Carrington *et al.*<sup>[36]</sup> studied the benefits of a plant known as bloodroot (*Justicia secunda*) applied topically to treat diabetic foot infections. They incubated bacteria extracted from infected foot wounds (*Staphylococcus aureus*, *Pseudomonas aeruginosa* and *Enterococcus faecalis*) and tested them against bloodroot, using ciprofloxacin as a control and dimethyl sulfoxide solutions as a negative control. In this study, bloodroot had no activity against the organisms tested. Carrington *et al.*<sup>[36]</sup> were able to show that this practice was ineffective, but the study design did not allow them to comment on its safety.

In a previous publication, we sought to determine whether the substitution culture was harmful<sup>[39]</sup>. We identified 695 patients who were admitted for diabetic foot infections. The outcomes of 382 patients who presented for conventional medical treatment as soon as their foot infections were identified were compared to 313 patients who made a conscious decision to delay medical therapy in favour of alternative therapies. This study<sup>[39]</sup> demonstrated just how strong the Caribbean substitution culture was: 45% of patients voluntarily selected non-medical therapy as their first choice, although 75% had previous hospitalizations for foot infections and 54% had previous amputations and/or operative debridements. It may be expected that more patients would have presented for early medical therapy, considering that they had prior experience with, and were acutely aware of, the dangers of diabetic foot infections. It took an average of nine days for these patients to admit that their alternative therapies failed, and only then presented to hospitals for conventional medical care<sup>[39]</sup>. But the most important finding was that, for the first time, it was conclusively demonstrated that this practice was harmful. The patients who voluntarily chose to delay their presentations had significantly more surgical debridements, longer hospitalization by an average of nine days and increased health care expenditure of United States \$10821.72 per patient<sup>[39]</sup>. There was also a notable trend toward more major amputations (9.3% *vs* 5.2%;  $P = 0.073$ ) in the patients who self treated<sup>[39]</sup>. Although this did not achieve statistical significance, we suggest that it was clinically important because amputees have been shown to have significantly reduced quality of life, independence and life expectancy<sup>[2,3,5,7]</sup>.

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## POLICY IMPLICATIONS

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Governments in the Caribbean recognized that diabetes was one of the non-communicable diseases that places a high demand on health care resources in the region. In response to this growing problem, the Heads of Government in the Caribbean convened in Trinidad and Tobago in 2007<sup>[4]</sup>. They formulated the CARICOM Port of Spain Declaration<sup>[4]</sup> that aimed to create and implement regional policies to improve the management of non-communicable diseases.

A three-tiered approach was adopted to address diabetic foot infections<sup>[39]</sup>: The first tier focused on primary prevention, attempting to promote healthy lifestyles, optimize metabolic control and educate persons with diabetes about foot care<sup>[3,4]</sup>; The next tier focused on secondary prevention, promoting early detection and prompt treatment of foot infections when they did occur<sup>[8-10]</sup>; and the final tier focused on creating evidenced-based treatment protocols suited to the Caribbean environment<sup>[11,12]</sup>. The Caribbean substitution culture directly impacts the first and second tiers of these public health policies.

From the point of view of primary prevention, dedicated diabetes clinics were opened at strategic high-traffic areas within the community that were easy to access<sup>[8]</sup>. These were state-funded facilities with no user fees generated at these points of care. This ensured that patients had unimpeded access to care. Additionally, these clinics were staffed by local nurses and medical practitioners. The healthcare workers were mostly Caribbean natives and were trained at the University of the West Indies, a regional medical training institution providing secondary and tertiary medical education that was geared to training practitioners for all 17 countries in the English-speaking Caribbean<sup>[40]</sup>. This was important because these healthcare workers could relate to persons with diabetes by using colloquial language, demonstrating knowledge of local culture and discussing common practices. In this way, the healthcare workers could build rapport and gain patient trust.

From the secondary prevention point of view, a network of public health centres were established across the nation with no user fees generated at the points of service<sup>[39]</sup>. A national referral policy was also implemented to ensure that patients were routinely evaluated by specialists at tertiary referral facilities in a timely fashion. Clear therapeutic protocols were also established<sup>[1-3]</sup> as a part of this national policy document.

The Caribbean substitution culture has the potential to underutilize these policies. Therefore creative solutions are required because these are different problems than those in developing countries.

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## NEXT STEPS / RECOMMENDATIONS

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Most Caribbean countries have implemented the above listed mechanisms to ensure that patients with diabetic foot infections have unimpeded access to medical care. Despite this, the “substitution culture” is evident in modern reports from Trinidad & Tobago<sup>[14,39]</sup>, Jamaica<sup>[41]</sup>, Barbados<sup>[6,9,42]</sup> and Guyana<sup>[43]</sup> documenting that patients still do not access medical care early. These reports suggest that the existing preventative strategies fall short of their expectations. It may now be necessary to re-think these strategies, taking into account the Caribbean substitution culture.

In order to address these practices, policy makers should be aware of the demographics of these persons and document the practices that exist. Harnarayan *et al*<sup>[14]</sup> examined 344 patients with diabetic foot infections who chose not to access medical care in favour of alternative therapies. They identified middle-aged, afro-Caribbean males at a mean age of 56.4 ± 12.4 years as the typical persons in whom the substitution culture is manifest<sup>[14]</sup>. Surprisingly, it was experienced patients who lived with diabetes for a mean duration of 13 years, that engaged in these practices<sup>[14]</sup>. This study is important because it allows policy makers to identify a specific target population to work with. Additional demographic information that would be useful to target this problem include the educational level of the persons with diabetes who engage in this practice. This should be a focus of future studies.

Patient education is already practiced in these settings as a part of the “three tier approach” described above. Persons with diabetes were counseled in state-funded diabetes clinics that were strategically placed in high-traffic areas in the community. Harnarayan *et al*<sup>[14]</sup> reported that the persons with diabetes who engaged in these practices were informed patients, 100% having been previously counseled on the dangers of diabetic foot infections. However, it was not stated whether medical practitioners who counseled these individuals had specific training in counseling methods. Therefore, it was unclear whether they were able to build rapport with patients. For example, the counselors could inadvertently build distrust if they maligned traditional practices or spoke down to patients in language they could not

understand. Alternatively, it would have been appropriate for the counselors to address these practices by distinguishing ones that seemed effective from those that were not and/or distinguishing practices that were harmful from those that might have some value and warrant respect.

Another way that the educational process could be improved would be to have pre and post-counseling surveys to determine whether the activity was successful in curbing patient beliefs and practices. If an intervention is not proven to be successful, then early change can be implemented.

Policy makers should always be aware of the alternative strategies that are in common use and study their outcomes. In this way, patient education can be directed. Ongoing research into this would also allow medical practitioners to identify specific practices that may be harmful to patients and distinguish them from those that may be beneficial. Patients may be appreciative of this approach. A good example is when patients pour hot paraffin wax, cooking oil or grease directly onto an infected wound. In persons with diabetes who have neuropathy, this could result in devastating thermal injury. In addition, we can point out that there is no standardized agent, dosing, frequency of applications or duration of therapy.

In some cases, legal means can be used. For example, we detailed a disturbing practice where persons with diabetes were able to purchase “pills” from unregulated streetside vendors with no awareness of the name of the drug or instruction on dose, frequency or duration of the drugs<sup>[4]</sup>. This demonstrates the severity of the problem because the persons engaging in this practice had such indifference for conventional medicine, that they were willing to pay “alternative healers” even though state-funded conventional health care was available to them free of charge. This could be curbed by policing and imposing penalties via the respective regulatory bodies.

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## CONCLUSION

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Although the Caribbean substitution culture appears to be a barrier to effective treatment of diabetic foot infections, there is little or no data on the driving forces behind these practices. Continued directed research is required to understand the substitution culture before it can be addressed effectively.

Conventional medical practitioners should start with the premise that these alternative therapies can be an important complement to the treatment of Caribbean persons. We should reassure these patients that the treatments need not be mutually exclusive and encourage them to simultaneously seek medical advice as a part of holistic care.

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