



Article

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Abstract: *The objective of this paper is to document the knowledge and experiences of healthcare professionals and researchers in Australia about the barriers to controlling Strongyloides stercoralis in Australian Indigenous communities. Qualitative research methods were used to conduct in-depth semi-structured interviews, which were digitally recorded, transcribed, and participant-checked. Data were thematically analysed to identify significant themes. Five major themes were identified:*

- 1. Barriers to health/treatment;*
- 2. Access to healthcare;*
- 3. Policy;*
- 4. Learning opportunity; and*
- 5. Ideas for intervention.*

The findings suggest that Australian Indigenous communities will continue to suffer increased morbidity and mortality due to a lack of control or prevention of Strongyloides stercoralis. Issues such as institutional racism, improvements to health promotion, education, socioeconomic determinants, and health care system policy and procedures need to be addressed. This study identifies several direct implications for Indigenous health:

- The need for increased knowledge and understanding of the risks to health for Indigenous community members;*
- The need for prevention policy development for neglected tropical diseases in Indigenous communities;*
- The need for increased knowledge and understanding of the treatment, diagnosis, and healthcare access concerning Strongyloides stercoralis for health professionals and policymakers who work within Indigenous health;*
- The need to raise awareness of systematic institutional racism in the control and prevention of neglected tropical diseases in Indigenous communities; and*

- *The need for a health promotion framework that can provide the basis for multiple-level interventions to control and prevent Strongyloides in Indigenous communities.*

Introduction

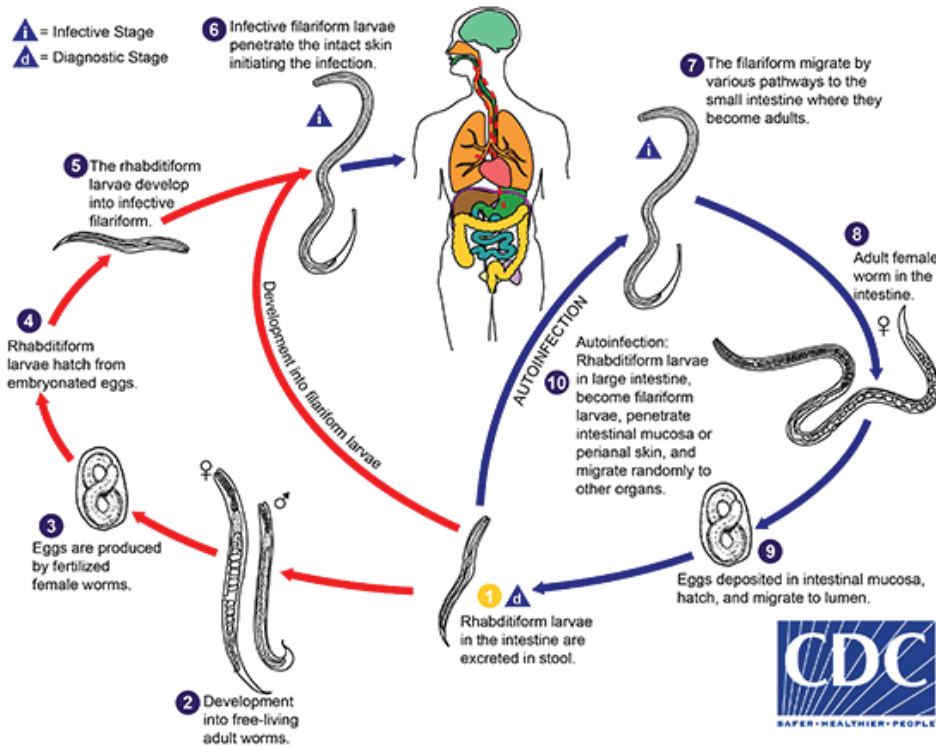
Infectious diseases contribute significantly to the morbidity and mortality of Indigenous Australians, particularly in rural and remote communities, at a much higher rate than in the mainstream Australian community (AIHW 2015; Holt, McCarthy and Carapetis 2010; Flannery and White 1993). There are many highly effective interventions for the control of these diseases. However, implementation of these interventions in rural Indigenous communities is frequently suboptimal. Barriers at multiple levels appear to impact on effective interventions in Indigenous communities.

Strongyloides stercoralis is an intestinal nematode transmitted by contact with damp soil containing infective larvae (Speare 1989; Sheery, Walker and Biggs 2000). These infective larvae are developed from faeces indiscriminately deposited on the ground. The larvae penetrate the skin and travel to the lungs, where they penetrate the alveolar spaces and are carried through the bronchial tree to the pharynx (Sheery, Walker and Biggs 2000). They are then swallowed and reach the intestines where they develop into adults that live in tunnels in the small intestinal mucosa (Sheery, Walker and Biggs 2000). The uniqueness of *S. stercoralis* is that it can become autoinfectious, with small infective larvae formed in the gut and re-entering the tissues by penetrating the wall of the lower bowel. The practical result of this is that a single infection can last many years and probably for life; the longest recorded infection is 65 years (Leighton and MacSween 1990). Also, if the immune response of the host is suppressed, the rate of successful colonisation by autoinfective larvae increases, the number of adult worms in the gut rises, and a serious and potentially fatal disease (the hyperinfective syndrome) develops.

The significance of strongyloidiasis in rural and remote Indigenous communities is that it is a highly infectious parasite, a disease with a unique life-cycle of autoinfection that causes a variety of symptoms, including fatality from hyper-infection and lifelong infection if left untreated (Johnson et al. 2005). Australian Indigenous people living in rural and remote settings are exposed to and are infected with *S. stercoralis*. Some of the highest prevalence levels in the world have been recorded in northern Australia, with a prevalence of 40% not uncommon in some groups (Adams, Page and Speare 2003). In most societies, the prevalence is under 5%, even in communities with severe poverty. The impact of the parasite on communities has been documented, including case reports of serious disease (Walker, Blake and Downing 1976; Yiannakou et al. 1992; Mak 1993). One case series (Kukuruzovic et al. 2002) showed that Indigenous children with acute strongyloidiasis and diarrhoea were more likely to have hypokalaemia (low blood potassium) than were similar children with diarrhoea due to other causes. Work has been done in remote Australian Indigenous communities with mass drug administration (MDA) programs such as those conducted by Kearns et al. (2009) administering ivermectin across communities to attempt

an eradication of scabies and strongyloidiasis. Recently, Kearns et al. (2017) focused on administering ivermectin for the treatment of strongyloidiasis across two remote Australian Indigenous communities. Both studies have presented research supporting that MDA programs incorporating routine treatment with community engagement and education can decrease and potentially eradicate strongyloidiasis (Kearns et al. 2009; Kearns et al. 2017).

FIGURE 1. The life cycle of *Strongyloides stercoralis* (CDC 2015)



Diagnostic tests suitable for use in Australian Indigenous communities are available. Speare and Durrheim (2004) estimated that detecting and curing a positive case of strongyloidiasis in these hyperendemic northern communities are relatively inexpensive, costing \$590 per case if community-wide screening were implemented. In Caucasian groups, chronic strongyloidiasis produces significant symptomatology in 67% of infected individuals (Grove 1980). There is no reason to believe this is not the case in Indigenous Australians. The diagnosis of strongyloidiasis in mainstream Australians with no risk factors, particularly related to travel history, is so rare that there are few to no published case reports.

A systematic review of the peer-reviewed literature published between 1969 and 2010 has presented the status of strongyloidiasis for Australian Indigenous community members and summarized the barriers to its control (Miller et al. 2014). The main barriers to management are health status, socioeconomic status, healthcare literacy, and procedures. Concurrent health conditions and infections, living conditions and racial disparities, the

difficulty of detection, and inadequate knowledge/treatment (e.g., medication dosage) are, but a few of the main barriers presented (Miller et al. 2014).

The barriers to controlling infectious diseases for health improvement at the personal level in rural and remote Indigenous communities include

1. communication difficulties between health staff and Indigenous patients based on the lack of a shared understanding of disease causation and the simple fact that English is not the first language for many people in remote locations (Trudgeon 2000; McConnel 2003; Cheng, Blum and Spain 2004);
2. fear of disclosure of culturally sensitive illnesses (Newman et al. 2007)
3. fear of discrimination (Lowe et al. 1995; Trudgeon 2000; Newman et al. 2007);
4. remoteness from essential specialised health services (Gruen, Weeramanthri and Bailie 2002; McGrath 2006);
5. lack of the funds needed to purchase medication and equipment (Couzos and Davis 2005; Couzos 2005);
6. the need for education in maternal and child health (Molyneux 2006);
7. the need for involvement from other government sectors and agencies (Molyneux 2006);
8. the need for the establishment of surveillance, diagnosis, monitoring, and evaluation systems (Molyneux 2006); and
9. at the population and governmental levels, the potential influence of racist attitudes negatively impacting health expectations and services (Lowe, Kerridge and Mitchell 1995; Trudgeon 2000; Aldrich, Zwi and Short 2007).

Although many barriers have been explored from the intervention perspective, no research has qualitatively explored the barriers from the Indigenous community's perspective—the health service staff working in Indigenous communities—or have documented the experiences of leading experts in the field outside of their clinical intervention or professional role.

Strongyloidiasis is not considered a notifiable disease in the Australian public health system (Speare, Miller and Page 2015). The purpose of this study is to describe the barriers for the prevention, treatment, and control *S. stercoralis* from the perspective of experienced researchers and healthcare workers in Australia. *S. stercoralis* infects humans mainly through skin contact with contaminated soil. In discussing the control of communicable diseases such as strongyloidiasis, the term “control” implies prevention. In this study, the authors want to make it explicit that prevention must be considered from a public health and Indigenous community perspective. The perspectives of researchers and community members affected by *S. stercoralis* or other infectious diseases have a better chance of influencing policy. Policy development about control and prevention must deal with and address institutional racism for successful implementation (including the key messages to government, researchers, and community members). For the purposes of this paper, the authors focus on these policy implications and therefore do not specifically explore the eradication of *S. stercoralis*.

In a systematic review of the barriers to the control of strongyloidiasis, Miller et al. (2014) described the need for a detailed, clinical picture in order to manage *S. stercoralis* in Australia, including prevalence rates, evidence, and community-based public health approaches to control strongyloidiasis. This study explores the barriers to the implementation of infectious disease interventions for diagnosing, treating, and preventing strongyloidiasis from the perspective of experienced healthcare professionals with extensive medical knowledge and experience in the field of researching and/or diagnosing and treating strongyloidiasis. The aim of this paper is to document the knowledge and experiences of these experienced healthcare professionals concerning strongyloidiasis in Indigenous Australian communities and to use their knowledge and experience to better understand the policy implications for controlling and preventing strongyloidiasis.

Methods

The study was conducted in Australia and focused on barriers to the treatment, control, and prevention of strongyloidiasis in Indigenous communities. The authors used a descriptive qualitative study to explore the perspectives of healthcare professionals as key informants for strongyloidiasis in the context of Indigenous communities, environmental health, and health care systems (Pope and Mays 2006; Pope, Reibland and Mays 2006). Purposive sampling was used to recruit health professionals and researchers with long-term experience with *S. stercoralis* participants. The participants in this study are described as health professionals who work within laboratories, research institutions, and primary health care services in rural and remote and urban settings from around Australia. Participants were eligible to be included in the study if they worked in Indigenous communities in Australia and/or had experience diagnosing and treating strongyloidiasis. Participant recruitment was undertaken by selecting nationally known health professionals and researchers working on the diagnosis and treatment of strongyloidiasis.

Telephone interviews were conducted with participants based on a semi-structured interview guide. Participants were provided with open-ended interview questions prior to scheduled telephone interviews. These open-ended questions focused on their experiences with the barriers to controlling *S. stercoralis*, including health care system/policy, drug treatment, the Australian public policy context, and the Indigenous community context. Probes were used to help participants elaborate on their experiences in the field. All interviews were audio recorded and transcribed verbatim. Participants were provided with a copy of their transcript to confirm and approve the accuracy of the transcription. No revisions were requested by any of the participants. Thematic analysis using constant comparison was applied to the transcribed interviews (Creswell 2012). Two members of the research team individually coded each transcription, and then the larger research team met to discuss the codes and develop the coding framework.

Research ethics approval was granted by the Human Research Ethics Committee of Griffith University, Brisbane, Australia. All participants signed an informed consent to participate in

their interview and to allow information and possible quotes to be published. Their anonymity and confidentiality were included in the consent process. However, some participants were not concerned about being recognized through the information they shared.

Results

This study identified five major themes and sub-themes as major barriers to controlling strongyloidiasis in Indigenous Australian communities: barriers to health/treatment, access to health care, policy, learning opportunities, and ideas for intervention (see Table 1).

TABLE 1: Themes and sub-themes

Major Theme	Sub-theme
1. Barriers to Health/Treatment	1.1 Perspectives of Racism <ul style="list-style-type: none"> • Infrastructure/Environment • Diagnosis/Treatment • Normalisation 1.2 Diagnosis/Clinical Knowledge <ul style="list-style-type: none"> • Diagnosis • Clinical Knowledge 1.3 Community in Context <ul style="list-style-type: none"> • Trust • Environment
2. Access to Health Care	2.1 Treatment/Medication
3. Policy	3.1 Government Funding 3.2 Institutional Racism
4. Learning Opportunity	4.1 Community Perspective 4.2 Ethical Research
5. Ideas for Intervention	5.1 Cost Effective 5.2 Knowledge Translation 5.3 Community Partnership <ul style="list-style-type: none"> • Identification • Health Promotion and Prevention Programs/Strategies • Registration/Prevalence

Barriers to Health/Treatment

Perspectives of racism

Racism is perceived at both individual and institutional levels, particularly in controls over accessing data and knowledge of the disease.

Infrastructure/Environment

The environment itself exposes a community to *S. stercoralis* infestation, an environment related to housing and infrastructure resulting from influences of racism that impede people from decreasing their exposure:

Some issues in the housing, in internal housing areas, but also the external housing area, in particular like compromised infrastructure, like overflow in septic tanks, leaking taps ... hardware. So we had a look at some behaviours, the activities of daily living in some of the houses, and where these wet areas or damp areas were persisting, and in particular the kids, basically, the external housing environments harboured the nematode.

Participant 1

Diagnosis/Treatment

A lack of education and knowledge among health professionals about *S. stercoralis*, including on infection rates, symptoms, and asymptomatic behaviour, can lead to misdiagnosis and ineffective treatment. The individual and institutional level of control of this necessary information perpetuates the issues described by health professionals in the field working with *S. stercoralis* infections:

Lot of challenges around diagnosis but diagnosis is important because if you get to a point where you fixed up the sanitation, and you've done your treatments, or all you do is a selective treatment program, or people come in, there are issues with diagnosis...the first issue of diagnosis is lack of education amongst clinicians that Strongyloides is a significant

Participant 4

.....

People have got multiple parasites, wouldn't it be good to treat them with ivermectin and do some follow-up? I don't get it; I honestly don't get why they only look at bloody treating bits and pieces and not looking at the whole raft of issues.

Participant 1

The only way people can actually get the medication is if they've had a blood test and it comes up positive so you're actually getting the appropriate drugs, and for adults it's relatively simple because they'd normally be taking blood anyway to check out for chronic diseases, and then they send it off for Strongyloides as well, but for children they hardly ever take blood from children unless they think it's absolutely, absolutely essential, so they never get tested and so they never get treated.

Participant 2

Normalisation

The assumption that people in the community are always ill and allowing it to continue as a "normal state" is a form of racism, as is the perspective among the people themselves that feeling ill is normal for everyone:

The process, it's called normalisation, so not feeling well becomes normal in the person's mind, and so if you're not unwell for a long period of time and somebody says how are you today, and you'll say I'm okay because you haven't been more sick, I suppose recently. They don't actually recognise that they've got the symptoms. They think it's normal to have diarrhoea all the time and belly aches and things like that...that process is normalisation.

Participant 2

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The terrible quotes that were around, it's only the sick who die. I've just found strange comments coming from medical profession and then a concept you could treat individuals, but somehow you couldn't treat the individuals in an endemic area just because it was endemic.

Participant 9

.....

There is a degree where even people who are very, very good people just see so much morbidity all the time that from that you just get habituated to seeing it. You become immune to it which is not, I don't think it's necessarily racism, it's not an acceptance that it's right, but it's just so often that you see these things...certainly you can get habituated to seeing people coming in with disastrous health problems and I think some people they just lose sight of the fact...I believe in the principle just because it's a remote Indigenous community, health care should basically be as good as somebody who lives in the city essentially, and except for distance and things like that, there's no reason you shouldn't aim for the same baseline. Poor sanitation is not acceptable in the middle of [Australia] so it shouldn't be acceptable in indigenous communities.

Participant 4

.....

Normalisation with regards to the disease actually comes from speaking to health care workers, community workers, people, other researchers who have actually gone into the communities to look at the issue as well...I think it's a growing issue.

Participant 7

Diagnosis/Clinical Knowledge

S. stercoralis infection is diagnosed via blood or stool sample, and both have diagnosis limitations/issues. Without diagnosis and subsequent treatment, the infection can lead to a suppressed immune system, life-threatening complications, and death.

Diagnosis

Stool testing is not ideal, as larvae are intermittent and are less likely to be observed in stool in chronic strongyloidiasis:

The fact that you can have chronic strongyloidiasis and you can treat it, but your subsequent source specimens will be negative and then like maybe seven weeks later one will turn up positive again. That's just the nature of the worm, that's just the nature of the beast. And the limitations with regard to finding the organism in the stool which requires live larvae to be present. There are issues in terms of specimen transportation with regard to that in Australia.

Participant 4

.....

Currently, the gold standard is faecal culture, and faecal culture has a lot of practical issues. We rely on fresh stool samples to have an effective specimen for culture. By the time a faecal sample, if submitted, reaches the lab it can be three or four days old and by that time the parasite's dead so we can't get culture, a positive culture, so it does concern me that we're issuing reports saying that the culture is negative and giving false negative reports...that's a practical issue.

Participant 5

Obtaining samples is often impeded by non-compliance. For example, non-compliance associated with obtaining blood from children or stool samples are barriers to diagnosis and treatment:

They're much more willing to give stool samples from little children than from older children. I think there's also the shame aspect of things too as well, but yeah it is harder to get stool samples.

Participant 2

Strongyloides infection can be either symptomatic or asymptomatic. The longer a person suffers from infection, the higher the risk of hyperinfection potentially leading to death:

Every test has its limitations, and part of the thing about clinician education is not just to be aware of strongyloidiasis but to be wary when all your tests are negative as well. Because they can be negative, but someone might still have strongyloidiasis. They probably won't on the basis of probabilities, but it comes down to a situation like hyperinfection, you can't be too careful.

Participant 4

.....

Under a microscope, you've got the situation of being able to diagnose it, but because it's in chronic strongyloidiasis, it's not necessarily showing in the faeces. It seems that phases you can diagnose it in the faeces are in the acute phase when someone's probably got diarrhoea, and it is their first episode or certainly when disseminated. When [larvae] is in its millions and in both those cases, the Strongyloides in serology is not as reliable. The body might not have developed its own immune response, and in disseminated strongyloidiasis, the immune system may be so low that it can't mount an immune response...in the primary care setting, we're really looking for identifying those that have chronic strongyloidiasis and then looking to treat that before they're actually running into the complications...people die from septicaemia. If you get to the disseminated phase which is when [larvae] multiplies into its millions having a drug that's going to kill something that's in its millions is very hard, and that's why disseminated strongyloidiasis has a high fatality rate.

Participant 9

Clinical Knowledge

The lack of clinical understanding of *S. stercoralis* leads to inadequate clinical practice, reduced health, and increased risk for people exposed. Health professionals armed with detailed information on *S. Stercoralis*, prevalence, diagnosis, and treatment would radically influence the infection rates amongst individuals and decrease the symptoms and concurrent health problems resulting from strongyloidiasis:

From a clinical perspective, I think working with the remote clinics, most of them don't know about Strongyloides, they wouldn't have a clue about it.

Participant 1

From the point of view of the clinician, I think probably an awareness of ivermectin and its role in eradicating Strongyloides.

Participant 6

Strongyloides can be symptomatic, asymptomatic, or both; it can mimic many other illnesses. If health professionals were more aware of this issue, they could have increased opportunities to make accurate diagnoses:

The fact that we don't really know how many of the ordinary everyday symptoms of ill health are caused by Strongyloides being inside the body as against other factors. And because some of the symptoms of Strongyloides infection can be nausea, vomiting, diarrhoea, rashes, not sleeping well, not eating well, all of those sort of common run of the mill symptoms of feeling crook, and we don't go that extra step of testing to see whether they've got Strongyloides or not but it could well be that in many instances that's the cause of the problem.

Participant 6

Failure to understand the complexity of the auto-infective cycle and incorrect diagnoses can lead to disseminated strongyloidiasis and to extreme decreased health, and potentially death:

You've got a health profession that are trained in Australia that are ignorant of Strongyloides, It's understanding about the auto-infective cycle and the fact that if you don't think of it, you're not going to diagnose it and the evidence is that those who die from strongyloidiasis, there's probably been warnings signs beforehand, but medical professionals have not been alert or aware of it to consider it, and my experience has been that when people do die they're actually preventable deaths.

Participant 9

Community in Context

Disease and infection can be described in the context of community. Lack of knowledge of the disease (including exposure and transmission processes), community experience with health professionals, and the community's environment and location all influence how strongyloidiasis is understood and how that understanding, in turn, influences barriers and outcomes.

Trust

Barriers within the community can include mistrust of the health professionals:

The sort of barriers that [non-community member(s)] encountered was a lot of mistrust, why are they taking my blood, are they going to take it and sell it to someone else and make a profit out of it, those sorts of thoughts...And there were some people who refused to cooperate and so they just moved onto another person.

Participant 5

Environment

A community's environmental health (or lack thereof) influences exposure and infection rates. Transmission rates increase along with reductions in environmental health:

Environmental health [government department] can say look you've got a problem; we're going to advocate, that sewerage system's broken down, go and get it fixed. The environmental health don't actually fix it, they have advocacy role to see that it's done and then you have the infrastructure that's managed by councils, managed by housing authorities, it's managed in a different section but they usually have responsibility for building appropriate housing.

Participant 9

Community awareness of ways to prevent transmission could decrease the exposure and transmission of *S. Stercoralis*:

It's actually poor sanitation, whether that's educational to some degree with the kids avoiding, say if the septic tank is broken avoid running around the outflow from the septic tank or whether it's just the infrastructure side of things and the good disposal of sewerage.

Participant 4

Diagnosing at the community level is challenging:

They say you need three stool samples, either consecutively or three stool samples over a week because the Strongyloides larva output is so irregular. And certainly, we only ever did it by a single sample. For us in community, it is quite difficult to get that one sample, let alone trying to get three...to get to the laboratory from a community, we're never going to see Strongyloides. What we have found is most of the kids have often got...bugs in their tummy. Then they're actually treated for Giardia when it actual fact it could have been the Strongyloides underlying it. We will never know. So they would have got the three-dose of albendazole in the community as a sort of protocol. By the time they get the poo sample back, I think we found that 50% or more of the kids had Giardia and Trichuris.

Participant 8

Access to Healthcare

Treatment/Medication

The inability to treat Strongyloides effectively and the difficulty of accessing health care influence the community's ability to prevent and treat it. By engaging a full-faceted approach

to prevention, a program should focus on improving the environment to decrease exposure to and infection of *S. Stercoralis*:

We concentrate on engaging those people in the house in regards to the cleanliness of the house, internal environment, but also the hygiene factor in the house

Participant 1

The difficulty of diagnosing Strongyloides contributed to a lack of treatment:

The other problem with ivermectin is basically the protocols...that unless the person has got a positive diagnosis for Strongyloides, they're not given ivermectin. If they're suspected of having it, but they haven't got a positive diagnosis, they will give albendazole, and they'll offer three doses, but they usually only watch one of them being swallowed, and we know that even three doses of albendazole on three different days isn't effective.

Participant 2

Disseminated Strongyloides leading to hyperinfection requires long-term treatment:

Go by the evidence ivermectin is superior to albendazole based on trials. So single dose ivermectin is superior to three doses of albendazole in terms of elimination and then getting a second dose of ivermectin two weeks later is marginally better than just giving a single dose of ivermectin. That's for chronic infection, if somebody's got hyperinfection it's a completely different story. You need to keep treating them until they get better and then after that even give them a bit more...in terms of the Australian setting, I can't think of any reason why you wouldn't give the people ivermectin provided they don't have a particular [no side effects taken with other medications].

Participant 4

The gastrointestinal condition of the person with Strongyloides influences the absorption rate of medication at the individual level. Ivermectin is safe and, with the correct therapeutic dose, will decrease infection rates:

Both ivermectin and albendazole are not that well absorbed through the gut, so we don't know what therapeutic blood levels are reached in individuals. You're going to get individual variation and variation due to the diet they take and the condition of their gut at the time of medication. Given that the medication is relatively safe it's probably still easier to overmedicate someone than to miss the Strongyloides infection.

Participant 5

Policy

The policy theme includes narratives around government funding and institutional racism. Control, normalization, and cost influence what illness or disease is declared important to public health, which in turn determines funding allocation for control, prevention, and drug treatment strategies and initiatives.

Government Funding

Recognizing outbreaks and having the staff to manage them is an issue:

Certainly, in the [location], we have the Centre for Disease Control, public health nurses and doctors that can provide guidance. But often when a community is having a big outbreak or a raised prevalence, they say at the Public Health Unit, can you [multidiscipline team] come and help us? With the high staff turnover in community, certainly not with the health workers, but with the...staff, people unless they've been around for a long time, they're nervous about shutting up shop for a week, and running around and screening and treating everybody.

Participant 8

Institutional Racism

Avoidance, denial, and normalisation of strongyloidiasis in communities have been described as institutional racism by public health and public policy:

Public policy arena there might be some endemic racism, there's still institutionalised racism...I know that the doctors and nurses generally don't exhibit that. What other reason can you come up with for as to why there is such disparity?

Participant 4

Institutional racism is expressed as a lack of focus on the health of Indigenous people:

I don't know it's one of those things where no one has gone to the trouble of doing anything about it for Indigenous people. I suppose it's one of those institutional racism things that health departments can be pretty guilty of.

Participant 6

The government's normalization and lack of urgency concerning illness affect communities with grandparents raising children orphaned by parents succumbing to disease (most often considered preventable):

When I first started working in the Department of Health it really annoyed me when people would say oh that's for remote; they can wait as if it wasn't very important that something should happen quickly. I think across the board everyone tends to forget that out there is people who are sick, who are very inconvenienced by whatever illness it is that they've got, and are dying at a very early age which means that you've got heaps of kids out there without any mothers or fathers. There's grandmothers and aunties who are looking after too many kids for what they deserve because they're looking after all the kids of the ones who've died. I don't know how you do it, but there's definitely this view held by a number of people in the bureaucracy that feel that because it's out bush there's no real hurry.

Participant 6

Further perspectives confirm that there is a lack of urgency concerning to need to supply medications to remote areas:

I suppose in pharmacy is where I first came across [institutional racism] and I'll never forget the first day that I was working in the pharmacy, and a heap of scripts came in which is about 500 kilometres away and if you were in a suburban pharmacy anywhere and a heap of scripts came in the size of the heap that came in that day you'd almost shit yourself. I won't get these done today. And when I said to the girl "wow when do they want these", she said, "oh it's all right, there's no hurry, a couple of weeks will do". That was the first impact that I had of this view that people out bush can wait. If a doctor's seen a patient and want them to have a drug, we make sure they get it as quickly as they can in the suburbs but if they live out bush there's nowhere near the same sense of immediacy, and because of that, people are not thinking that their medicines are very important.

Participant 6

It is reported that Australia's Indigenous communities are lacking basic needs and health care:

It's a disease considered of a third world country, so it's not considered a mainstream issue, and because the decision makers live in probably first world conditions and just doesn't affect the decision-makers I think that's the reason that nothing's done or things that can be done aren't actually addressed, and I think particularly for remote Indigenous communities, out of sight is out of mind and that applies to other things.

Participant 9

The status of Indigenous communities appears to continue to be deemed lower than that of other communities, leading to a lack of urgency in healthcare provision:

The bureaucracy don't see it that way but if you see it as institutional racism because if it were white people in their own suburbs in mainstream set up, they'd be thinking.. better do something about getting rid of it, I suppose the bottom line is when something affects you, you're more likely to want to see something done about it...the people that aren't in influential positions are less likely to have their issues addressed than the ones who are in influential positions.

Participant 9

Learning Opportunity

Combining clinical and community perspectives has the potential to improve health in communities, including the eradication and treatment of strongyloidiasis and ongoing ethical research.

Community Perspective

Community involvement and engagement in all aspects of research are imperative: We set an engagement process with community...I think it's best practice, so it shows people, researchers or whoever's coming in to do this type of work or research work, know how to actually engage in a community...we tested the engagement process pretty rigorously, and we used it on multiple sites, and we never, ever, ever had an issue with engagement on a community with it.

Participant 1

Non-Indigenous health professionals need exposure and learning opportunities within the community for greater awareness and understanding of what is needed:

Because we had non-Indigenous clinicians with us, they just grew from this experience; they were just overawed with it. So it was about learning, and also it was about them learning of how we operate as well, and what benefits they can get from our way of learning and implementing these things, but also incorporating their views. Their views were valued too; incorporating their views into our stuff, and how we can fit in with that and they can fit in with us.

Participant 1

.....

The next step it is really important for us to link with communities and with patients and hope that they are willing to let us in.

Participant 3

Indigenous community Elders play an integral role in the community and need to be included:

Aboriginal Elders participating in the discussion and ways of educating community leaders...I think their involvement in spreading the information is vital in terms of getting control programs going. I think to any success has got to come from them and be supported by them.

Participant 5

There must be ongoing community training within the community to foster a better understanding of and engagement with health issues in more acceptable ways:

I've found for certain drugs and certain conditions; we don't always need health workers, nurses, doctors, to do stuff. But if we do want to focus on a particular disease or illness, then we actually can train people up with enough information to actually

be able to go out and do work in the community - it's often a lot more acceptable for the community workers to go and sit in a home and have a chat about what's going on than to try and drag people to the clinic or for the clinic staff to go out.

Participant 8

Ethical Research

Research needs to be conducted with the community, not on the community, along with appropriate feedback to the community so that appropriate actions can be implemented to address the issues:

Our research with community, I got a letter of acknowledgement for the research [from] all the traditional owners on that site and from that area, and when the research was finished we went around to all those traditional owners and sat there and explained what we needed to explain properly,...and they signed the acknowledgement that we'd consulted and everything in regards to the completion of the research. Now I've never, ever seen that data on any research paper that I've read, I've never, ever seen it done...We need to get that message out that people need to explain research and what are the benefits of the research for the people who are going to be part of the research.

Participant 1

In working with the community, Indigenous viewpoints must be included in research: [An] ethics approval process [must] allow for an Aboriginal viewpoint in regards to who we can talk to, who we can't talk to, who we're supposed to be talking to, who holds data, who's responsible for data, and who ultimately owns the data.

Participant 1

Ideas for Intervention

Cost Effective

Cost-effective health care in the long term is essential. Appropriate policies for treating and preventing Strongyloides must be established, including finding appropriate drug producers from other companies/countries if necessary. Ivermectin is safe and cost-effective and is the best evidence-based treatment:

[Ivermectin] is not expensive in terms of, in comparison with some other drugs.

Participant 2

.....

I completely believe in that holistic thing. And, if you can combine a couple of things like scabies and Strongyloides, you know how they come together because it was a one drug, and you certainly see that with lots of MDAs [Mass Drug Administration].

Participant 8

.....

You'd probably, in the long run, save a fair bit of money by reducing morbidity for other diseases too in terms of lifting people out of the impoverished sort of living circumstances.

Participant 4

Knowledge Translation

There must be a shift from dated clinical perspectives and medical models to a multidisciplinary, multifaceted innovation. Knowledge translation as described by the Canadian Institutes of Health Research encompasses an integrated approach and sharing of knowledge between researchers and knowledge users (e.g., government, public health, and community; CIHR 2016). In this circumstance, knowledge of *S. stercoralis* (the parasite) and strongyloidiasis (the disease) must be shared with all affected communities:

Information [must] get out to the remote communities [to increase] their level of knowledge and understanding of this infection.

Participant 5

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I think in a first world country like Australia; we should be able to expect that a condition that is an infectious chronic disease that's transmissible through poor sanitation should be something that is notifiable and then you have appropriate public health strategies to address it.

Participant 9

Knowledge translation among health professionals and communities increases education about *S. stercoralis*, which is crucial for treating and preventing strongyloidiasis:

You need education for GPs, the health professionals. You need education for the community, and then the next group will be that environmental health group that are monitoring what's happening in the environment.

Participant 9

Community Partnerships

Community-based partnerships along with community acknowledgement and respect for community/traditional owners are essential components of any intervention.

Identification

Intervention begins at the identification of each community:

Identifying the communities that are affected...my thinking has been that the ones that are most neglected are the ones that are then going to be identified.

Participant 9

We need to acknowledge that the community's need of a particular level of health service is as important as the needs of urban areas:

In the infrastructure of the way primary health care is delivered to people, you've got to make sure that your systems are in place to ensure that people out bush get as close as possible to the same level of service as people in the suburbs in mainstream.

Participant 6

We need to move away from treating on an individual case-by-case basis toward a community-level approach and intervention:

I think it requires a massive undertaking from community members as well as from the treating health centres to actually make that happen. Policy-wise, for Strongyloides, I'm still a little bit out on that. At the moment we treat individuals. And I haven't done enough analysis yet to see how much of that is household clustering. At the moment, policy-wise for Strongyloides, we just treat the person. We don't even screen the rest of the household.

Participant 8

Working with the community to identify their specific circumstances and needs in order to plan strategies and outcomes is important:

Each community is unique, as you know, and each community gazes in different ways, and we've got to work out and do the homework on how which engagement process will work to get the maximum benefit. You're looking at a multifaceted approach in regards to the engagement process.

Participant 1

Health promotion and prevention programs/strategies

Health education and promotion are ways to involve the community in eradicating strongyloidiasis. Engaging children about the benefits to their health and well-being of understanding the parasite is a key message:

Kids were integral to that little project and yeah, frigging fantastic. We followed up on it too, with health education and health promotion, and we integrated the regular worming cycles and that with the child health checks. Everyone's happy there, no one's got worms, they're going to school, the houses are clean.

Participant 1

Community engagement activities need to include adults and children:

Would be good if you got the adults educating the kids, so you teach the adults and the community health workers or whatever or other adults. Then the parents would know that too to be more careful of it because you're teaching the kids so it would stick in their mind a bit more too.

Participant 4

With support, community representation can enhance diagnosis and treatment strategies:

There has been some attempt in educating people in remote communities in regards to this infection, and once they are convinced of this worm and the presence of this worm, usually they're quite supportive in the program. Whether or not the government authorities will support and fund the diagnosis and treatment of this infection. I think it varies. The more community voices that speak up in regards to removing Strongyloides from their communities the more effective it would be.

Participant 5

Strategies need to focus on concurrent infections and conditions:

Mass treatment's the go because you're not only looking at treating for Strongyloides if you give someone ivermectin you're looking at all the other parasites and things you can kill as well. And these people should be thinking outside of the square because most of the people on the community and the kids are, they're polyparasitised, so they've got multiple parasitic infections, not just Strongyloides. If we're going to treat, we're going to knock on the head all these other things that are impacting on people's lives as well.

Participant 1

Kids should be mass-treated for all worms:

You've got the potential to [do] the de-worming for all the kids, to be able to have kids de-wormed. We don't test the kids because we don't do blood on kids but the kids could be de-wormed with ivermectin and albendazole and then the adults at the time you're doing the blood...and then you follow them up if they've got a positive result and then you've got the education

Participant 6

Treatment programs must include the people and their environment. Public health approaches with standard guidelines continue to be required, but innovative strategies must be incorporated to be flexible and fluid at the community level in order to treat and decrease Strongyloides:

Existing policies and guidelines, however, if you're looking at it from a clinical perspective it's very narrow, like the CARPA manual (CARPA 2014), it's quite anal, we look at it and think, "Oh yeah, just chuck a pill down someone's head, and that's all." Well, that's not how it's going to work. By having those policies and procedures, they need to be innovative and open enough to be able to do innovative work and not rigid.

Participant 1

A main element of any treatment protocol must be the environment:

It's very simple; it comes down to nineteenth-century public health measures. If you can bring in the nineteenth-century public health measures...you do a bit of treatment, whether it's selective mass treatment or mass treatment or just individuals when they come in sick, and that's enough awareness of it to consider strongyloidiasis, it doesn't really matter. But it just comes down to basic sort of bread and butter sanitation issues I reckon.

Participant 4

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The issue is whether or not you do a mass treatment program and I think that if you do a mass treatment program without having improved sanitation you're actually wasting your time to a degree. That said, you can't write these things off, but the sanitation is what keeps it going.

Participant 4

Eradication via routine drug administration could be an accepted protocol in community treatment programs:

For Strongyloides control...a once-yearly mass drug administration can drop the prevalence of Strongyloides very quickly.

Participant 8

The routine screening and treatment of many people increase the accuracy of prevalence rate measurement:

It would be good if done as a routine and would also give you more of an idea of the prevalence. But obviously there's a selection bias because it's only people presenting with diarrhoea, but it's a start. It's also a marker for programs designed...in terms of eradication so if you were going to do selective mass treatment you need to have some sort of marker as to an outcome or improve sanitation.

Participant 4

Developing innovative technologies may increase testing success:

Unfortunately, we don't have any point of care test which would be useful. I think what is needed is some testing system that can be done with low technology so that we don't rely on collecting the specimen and sending it into a major centre for testing, [so] it can be done out in a field laboratory type environment.

Participant 5

Registration/Prevalence

Gaining a better understanding of Strongyloides and of the full extent of the prevalence of the parasite requires that a national registry be created. Monitoring *S. Stercoralis* is necessary for an effective and long-term intervention. Our understanding of infection, transmission, and prevalence can be improved through registration similar to that used for other diseases like scabies:

There have been suggested approaches to having a Strongyloides register so that we can tell which individuals are infected or have been infected and it remains on their record so that if further down the track treatment has been effective then the Dr. can re-treat that individual. In terms of spread of this infection if you have a register, you can see or track where it's likely to, spread, to occur.

Participant 5

By monitoring the details of infection, protocols can be developed to address the particular circumstances/situations associated with infection:

The first thing I'd do is make strongyloidiasis notifiable, so you could actually gather your data for who was positive and then do some mapping...a register to gather all of that information to answer some of the questions for a disease that hasn't had much research go into it, and then you've got the general practice primary health care setting, and that can have a protocol for people coming through.

Participant 9

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The information and the access to data and the clarification of data coming out... doesn't acknowledge the incidence of Strongyloides.

Participant 1

Discussion

This study presents perspectives from experienced health professionals and researchers working directly with Australian Indigenous communities who treat and diagnose infec-

tious diseases, specifically strongyloidiasis. The overall themes presented were barriers to health/treatment, prevention, access to health care, policy implications, learning opportunities, and ideas for intervention.

Barriers to Health and Treatment

The key themes for *S. stercoralis* infection and subsequent acute and chronic disease included racism, diagnosis/clinical knowledge, and community in context. As shown in Miller et al. (2014), racial disparity and living conditions comprise the situational context influencing the key barriers. Continued unsanitary living conditions in communities increases *S. stercoralis* exposure. Environmental health policy is necessary for effecting changes in housing infrastructures, functioning plumbing, and enhanced sanitary hygiene and toileting in communities. *S. stercoralis* thrives in unsanitary communal areas (e.g., flooring in housing and outdoor leaking plumbing with exposure to faeces are active agents for strongyloidiasis infection and transfer). *S. Stercoralis* is diagnosed more frequently in rural and remote communities and is often associated with limited access to toilets or non-functioning sewage facilities (Kaminsky, Reyes-Garcia and Zambrano 2016). Concerning racial disparities, racism is perceived by participants in the lack or absence of public policy addressing environmental health issues and funding designed to make changes in affected communities.

Diagnosis and Treatment

Diagnosis continues to be difficult, as Strongyloides has a wide range of symptoms and opposing situations of asymptomology. Hyperinfection, HIV/AIDS, chronic alcoholism, malignancy, tuberculosis, chronic malnutrition, chronic renal failure, and exposure in endemic countries are all found to be factors associated with strongyloidiasis (Kaminsky, Reyes-Garcia and Zambrano 2016). Diarrhea is a significant symptom across patients with strongyloidiasis diagnosis. Strongyloidiasis often appears asymptomatic as presented in a six-year-old child (no abdominal pain, diarrhea, cough, urticarial or pruritus, wheezing, or skin abnormality) and in a survey of stool samples of children in Viti Levu Fiji (Kim et al. 2016; Zubrick et al. 2004). One case presenting at hospital with one week of abdominal pain and distention and vomiting was determined to be hyperinfection symptoms, later including a necrotic jejunal area and respiratory failure. The individual was treated with ivermectin, albendazole, and a broad-spectrum antibiotic. Unfortunately, mortality occurred after 32 days of hospitalization (Figueira et al. 2015). High-risk patients (such as those with the factors above) require mandatory screening prior to steroid treatment for quick and efficient diagnosis and treatment and to clear infection and avoid the hyperinfection and dissemination that can result from prolonged diagnosis (Kaminsky, Reyes-Garcia and Zambrano 2016).

The lack of knowledge among practitioners and community members of *S. stercoralis* and its required treatment strongly indicates the continued need for research, awareness, and policy changes. The findings of this research indicate a notable lack of knowledge about strongyloidiasis. Kaminsky, Reyes-Garcia, and Zambrano (2016) described issues in

Honduras similar to those Miller et al. (2014) described in Australia, including a failure to recognize symptoms, an inadequate knowledge of treatment protocol, and a lack of interest in defining and raising awareness of *S. stercoralis* infection in the community.

Access to Health Care

The 2014 Aboriginal and Torres Strait Islander Health Performance Framework Report (AIHW 2015) supports the perspectives of the participants interviewed for this study. Data on infectious and parasitic diseases (2008–2012 data) report that mortality rates per 100,000 were higher for those identified as Indigenous (19.4) than for those identified as Non-Indigenous (9.2). In addition, 29.9% of those identified as Indigenous aged 15 years or older reported problems accessing services, with 42.0 % located in remote areas and 25.9% in non-remote areas (2008 data). The Health Performance Framework Report (AIHW 2015) reported that the barriers to accessing health care services for remote areas were as follows: “no services in area” (23.7%), “not enough services in area” (20.5%), “waiting time too long or not available at time needed” (15.9%), “services not culturally appropriate” (2.5%), “don’t trust services” (3.3%), and “treated badly/discriminated against” (1.4%).

Policy

The perspectives about institutional racism and normalisation reported by the health care professionals in this study present a strong message for policy analysts and developers. Institutional racism refers to the ways in which beliefs and values have been built into institutional operations (e.g., social, health) in a way that discriminates against, controls, and oppresses groups (McConnachie, Hollingsworth and Pettman 1988; Henry, Houston and Mooney 2004). Henry et al. (2004) state that institutional racism can be covert, unrecognized, or unacknowledged by those in the institutions. They outline particular examples in Australian health care, including (1) funding inequality, (2) different performance criteria for black and white, (3) “body part” funding, (4) differences in treatment regimes, (5) inequitable Medicare Primary Health Care (Medicare Benefits Schedule plus Pharmaceutical benefits scheme), and (6) cultural barriers to the Indigenous use of healthcare services (Henry et al. 2004).

The Commonwealth Department of Health and Aging (2001) reported some of the same barriers to access in Indigenous health, including poor, unwelcoming interaction within private, government, and specialist sectors of health services. The National Aboriginal and Torres Strait Islander Health Council (NATSIHC 2003) report lower use/access to health services despite decreased health status and increased health care needs. They point out the need to prioritise allied health care, aged care, and acute care in Indigenous health. In 2002, the National Health and Medical Research Council (NHMRC) suggested areas for reform in Indigenous health and reported specific issues described as barriers to health system access, such as living with racism and poverty. The NHMRC (2002) proclaims that health services delivery is determined as a risk resulting from low levels of trust in health care and a need to understand what effective, accessible health services are and the reasons

why services fail. Further, the focus needs to be on equality in health care and improving health systems and cultural safety.

Although efforts toward policy changes for Indigenous health have been made in Australia, there continues to be a disparity in health and social outcomes (Anderson et al. 2006). Gaps continue to exist in local/regional health information systems in terms of both development and feedback, as well as a lack of Indigenous contribution to health frameworks and indicators for supporting Indigenous health (Smylie et al. 2006). Similarly, Tang and Browne (2008) argued that race and racialisation exist within the Canadian health care system, that health care is not free from discrimination, and thus that issues with socioeconomic contexts result in inequitable access to health care. Hole et al. (2015) suggest that dealing with issues of visibility and voice to foster cultural safety and reporting health care quality improvements such as practice, policy and environmental strategies are needed. In 2010, the NHMRC re-evaluated the continued disparity in the health and social outcome statuses of Indigenous health in Australia and streamlined and redefined the suggested priorities and objectives. The objectives shifted to (1) promoting knowledge transfer at the community level to provide input to service planning; (2) identifying health infrastructure requirements; (3) evaluating increases and risk factors in chronic conditions, and (4) evaluating models of care (NHMRC 2010).

Learning Opportunity

Developing practices in collaboration between health authorities, health professionals, and communities is essential (Hole et al. 2015). Coordination and planning that includes community perspectives and engagement and public health approaches (Einseidel and Woodman 2010; Shield and Page 2008; Miller et al. 2014) will improve health outcomes.

Ideas for Intervention

The data analysis in this study defined cost, knowledge translation, community partnerships, and registration/prevalence as key factors for strategizing interventions. These factors combined would increase intervention successes. Affordable drug costs, permitted by the Australian drug scheme (PBS), would increase access to ivermectin (NPS Medicinewise 2014; NPS Medicinewise 2015), the most effective treatment for strongyloidiasis. Knowledge translation requires active collaboration with communities, public health organisations/agencies, and researchers at all steps in the process—from identification, through procedure and research, and finally to intervention strategies—along with continual feedback for all partners is an elaborate strategy defined and supported by the Canadian Institutes of Health Research (CIHR 2016). To ensure knowledge translation, community partnerships must be developed by identifying each community and their context to ensure the full development of community engagement, recognition, and inclusion by all those in the partnership.

Registration and tracking the prevalence rates of *S. stercoralis* and strongyloidiasis can establish numbers for policy development and assist in the development of intervention

strategies by the community, public health organisations/agencies, and researchers. These factors, either separately or, preferably, as a combined strategy, are significant for policy. Public health policy that develops interventions and guidelines for diagnosis and treatments are essential (Miller et al. 2014; Adam, Page and Speare 2003; Soulsby, Hewagama and Brady 2012; Speare and White 2001; Shield and Page 2008).

Implications

This study offers direct policy implications for Indigenous communities. The need for policy development aimed at the prevention of neglected tropical diseases in Indigenous communities is highlighted. Increased knowledge and understanding of treatment, diagnosis, and healthcare access concerning *S. stercoralis* among health professionals and policymakers are necessary components of positive outcomes for Indigenous health. Raising awareness of systemic institutional racism in the control and prevention of neglected tropical diseases in Indigenous communities is required for effective and sustainable change. A health promotion framework can provide the basis for multiple levels of intervention to control and prevent Strongyloides in Indigenous communities.

Limitations

Few health professionals in Australia have extensive knowledge of the *S. stercoralis* parasite, infection, diagnosis, and treatment or experience with Indigenous communities. The authors interviewed many of these professionals and reached saturation but acknowledge that the sample was limited.

Conclusions

This study highlights the importance of the evidence-based reporting and declaration of strongyloidiasis as a notifiable disease (Speare, Miller and Page 2015). Barriers to controlling strongyloidiasis have been identified in this study, in line with previous research (Miller et al. 2014; Speare and White 2001; Page and Shield 2005; Kaminsky, Reyes-Garcia and Zambrano 2016). In-depth interviews with health service providers active in the field support this evidence. Raising awareness of institutional racism within the health care system, as described by the health professionals in this study, can contribute to policy change. The health care system cannot adequately address the barriers to prevention, treatment, and control until this institutional racism is brought to the forefront of policy development and change.

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