

SAGE Research Methods Cases

Medicine & Health

Submission for Consideration

Case Title

Reflections on Qualitatively Investigating HIV and Mental Illness Stigma in Botswana with a Multi-cultural and Multi-national Team

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Published Articles

Becker, T. D., Ho-Foster, A. R., Poku, O. B., Marobela, S., Mehta, H., Cao, D. T. X., ... Yang, L. H. (2019). "It's When the Trees Blossom": Explanatory Beliefs, Stigma, and Mental Illness in the Context of HIV in Botswana. *Qualitative Health Research*, 29(11), 1566–1580. <https://doi.org/10.1177/1049732319827523>

Additional articles pending

Abstract

Stigma presents a major public health challenge across the world, negatively impacting quality of life for people affected with diseases (including HIV and mental illness) and posing a barrier to optimal use of health services. The southern African nation Botswana has one of the world's highest HIV rates, and research has found particularly high rates of HIV among women with mental illness. In a collaboration between United States- and Botswana-based researchers, we conducted focus groups and interviews with people living with HIV (PLHIV) and members of the general public, in order to better understand culturally salient nuances of HIV stigma in Botswana. As an exploratory part of the study, we also explored beliefs and stigma related to mental illness. In this case study, we review study procedures, including forming a multicultural team, training researchers to prepare for fieldwork, recruiting and interviewing respondents on sensitive topics, challenges with transcription and translation, and analytic considerations. This study may be of interest to researchers conducting qualitative research outside their home setting, working across

multiple languages, working with vulnerable populations, and working as part of a multicultural and multinational team.

Learning Outcomes

By the end of this case, students should be able to:

- Understand how to design a qualitative study with considerations for work being done in low- and middle-income settings with a multicultural and multinational team
 - Describe differences between team coding and single coder approaches to qualitative analysis
 - Describe differences between inductive and deductive approaches to coding qualitative data
 - Critically assess ethical considerations when conducting research on sensitive topics in cross-cultural settings
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Case Study

Project Overview and Context

We sought to investigate the nature of stigma related to HIV and mental illness in Botswana. Our team, led by a US-based researcher with a focus on cultural aspects of stigma (LHY), also included researchers with experience in HIV programs and mental illness, students in public health, medicine, and psychology, and local practitioners in Botswana. There were several reasons for conducting the study in this setting. Botswana, a southern African country with a population of two million, has one of the highest rates of HIV in the world (~20%). However, due to wealth from diamond mining and a visionary government, the government has provided free anti-retroviral therapy (ART), since 2002, serving as a

model for the region. Despite these long-standing efforts to provide free services to care for people living with HIV (PLHIV) and control the epidemic, rates of treatment still fall short of goals, in part due to stigma (Ramogola-Masire et al, 2020). On a practical level, several investigators were already involved in a longstanding research and education collaboration between the Botswana health system and the University of Pennsylvania. As a result of this pre-existing partnership, the current study was able to build upon relationships and research infrastructure that had been developed through the hard work of prior studies. These relationships were essential to allow conducting a study on sensitive topics with vulnerable respondents.

The concept of stigma can provide a powerful framework for understanding barriers to care, by identifying social and cultural circumstances that influence behavior and the experience of illness in particular settings. Specifically, we applied What Matters Most (WMM) an influential theory of stigma developed by the study's principal investigator (Yang et al, 2007), which seeks to identify activities that are essential to being respected as a full person in a particular setting. For example, activities such as having children, helping others, engaging in religious practices, or having a job, take on different significance in different contexts. Per WMM, stigma is felt most strongly when it interferes with these activities. One of the main research goals of the project was to identify WMM in Botswana, in order to use the identified concepts to later develop measurements and interventions to reduce stigma.

Although HIV stigma was the main focus of the overall study, we also collected data on mental illness stigma. There were a few reasons for gathering this additional content. First, there is very little research about mental illness in Botswana, which, like many surrounding nations, has a limited mental health infrastructure. Second, a recent study by some members of the study team had found particularly high rates of HIV among patients admitted to the country's lone psychiatric hospital (Opondo et al, 2018). Although HIV and

mental illness are known to co-occur in North American populations, the social and cultural mechanisms linking these in southern Africa are less well understood. Therefore, questions about mental illness were included at the end of the study interviews to explore local perceptions of mental illness.

Since we ultimately gathered a lot of data, we made the practical decision to analyze the HIV half of the interviews and the mental illness half through separate processes, with separate codebooks, research questions, and coding teams. The case study that follows refers to the study overall, but with a particular emphasis on the mental illness part of the study. However, since at times we decided to use different methods for the two analyses (HIV and then mental illness), we compare differences when possible in order to illustrate possible reasons for choosing one method over another.

Section Summary

- *This study took place in Gaborone, Botswana and examined HIV and mental illness related stigma.*
- *Stigma can be a powerful force for understanding barriers to health services use*
- *The What Matters Most theoretical framework was applied to guide our research questions and study design in order to understand stigma in this setting.*

Research Design

Research Team

This study was designed to be an exploratory analysis of stigma related to both HIV and mental illness, with a particular emphasis on culture. We felt that the use of qualitative

methods would be best since qualitative methods allow for answering questions such as “how” and “why” something, such as stigma, occurs in a specific culture. These methods ground the “how” and why” within the everyday experiences of respondents through the use of interviews, narratives, and other methods to capture personal experiences (Kuper et al., 2008). With our focus on cultural understandings of HIV and mental illness, we knew that having a team of local experts would be essential when it came to designing interview instruments that would not only be contextually appropriate but also include cultural idioms that would help better capture respondent answers. One of our first steps was identifying and communicating with local researchers from the Botswana-University of Pennsylvania partnership who would be able to serve as key informants, whom we refer to as cultural experts throughout this case study. Key informants are individuals with in depth knowledge of a particular topic and/or population of interest (Sweetland et al., 2014).

In addition, we also believed it was important to have local research assistants (RAs) to collect the majority of the data for the study because they would have the language and customs needed to ensure respondents were comfortable, especially given our sensitive research questions. Again, our cultural experts who were also local researchers were important in that they helped in the recruitment of three RAs. Each of the RAs had a university level education and had participated in research before. In order to orient them to our study, we held a one-day qualitative training workshop that detailed the use of semi-structured in-depth interviewing as well as focus group methods. It was also important to provide detail about the WMM framework for them to have the foundational knowledge as to the types and reasons for the particular questions we were asking. Another useful tool for training was having the RAs complete the Collaborative Institutional Training Initiative (CITI) certificate for responsible research practices and ethics, an online training program which focuses on human subjects research. Finally, the RAs also shadowed the PI during the

first two focus groups to have an example as to best practices for interviewing groups of individuals. During the training session we also encouraged the RAs to ask questions and make modifications to the drafted interview and focus group guides given their wealth of social and cultural knowledge. This led to an iterative process of having a dedicated team of cultural experts who could continuously suggest changes to the data collection instruments and questions to better meet the needs of our research interests. The inclusion of local RAs can not only help in ensuring a contextually and culturally oriented group of investigators to engage with respondents, they also add to a study's team of cultural experts.

Recruitment

From reading the stigma literature, we were aware that stigma is typically studied from the perspective of people with a condition (internalized or self-stigma), people without the condition in the community (public stigma), or people with a relationship to people with a condition (e.g., family). In the examination of HIV stigma, we prioritized understanding *both* self and public stigma related to HIV. We contacted a large public clinic that has been involved in numerous prior studies, explained the study aims to clinic staff, and they agreed to assist us in recruiting their patients to provide a perspective on stigma from the point of view of a PLHIV. In order to obtain the perspectives of the general public, we recruited respondents from a heavily trafficked public square and asked them to schedule a time to be interviewed at a nearby community center. We considered but ultimately did not recruit a sample of people identified with mental illness due to logistical and ethical considerations and the more secondary and exploratory nature of the mental illness section of the study. Specific sampling procedures will be detailed below.

Data Collection and Management

For data collection, we decided to specifically use both focus groups and semi-structured individual interviews for a few key reasons. First, focus groups are great for getting at cultural saliency in a collective manner. When individuals of a cultural group are in a focus group, being able to understand what concepts are largely agreed upon versus disagreed upon helps researchers obtain a sense of concepts that are important in a culture (Rodriguez et al., 2011). Typically focus groups involve between five and eight individuals with a researcher and in some cases a notetaker (Gill et al., 2008). We held five focus groups which had on average five respondents with a researcher and notetaker who made it a point to mark questions that generated lots of interest or specific answers that resonated with the group. In addition, because focus groups allow for many respondents to be involved, we also used them first in the study to refine specific interview questions. This process was helpful in us then modifying questions drafted for the semi-structured interview guides to have a greater range of questions that we already knew respondents were comfortable answering.

We felt it was additionally important to use semi-structured interviews as a way to have more in-depth and specific examples of experiences with both HIV and mental illness stigma. Even though the focus group and interview questions did not differ greatly, having a one-on-one setting to ask about thoughts, feelings, and behaviors related to HIV and mental illness stigma was another way to get rich responses to inform our desired cultural understanding. We used semi-structured guides for both focus groups and individual interviews because we were asking questions based off of the WMM framework which meant that we had specific questions that we wanted to ask. However, we did not want to limit ourselves to using a fully structured interview guide, which are often used in quantitative methods. Semi-structured guides allowed us to ask our WMM questions and then probe, or

ask additional questions, about examples that respondents brought up. Overall, this method worked very well for us as we had a variety of experiences from respondents that led to multiple themes explored during the data analysis.

After the focus groups and interviews, we had a good yet still challenging situation on our hands. Our study is quite large comparatively to other qualitative studies (Vasileiou et al., 2018) as we had approximately eighty respondents inclusive of focus groups (n=38) and individual interviews (n=42). The focus groups and interviews were audio recorded and thus needed to be transcribed for qualitative data analysis. We also had a translation phase that had to be done at the same time as transcription since some respondents preferred to respond in Setswana, the local language, and our data analysis was conducted in English. We had to come up with a systematic way to take all the audio recordings we had, not lose track of the responses, and efficiently get transcripts ready for the analysis phase. This is where hiring the local RAs was of additional importance. We decided to divide all the transcripts among them and each had a specific group to work through on a weekly basis. This was a systematic way to track the recordings that were becoming transcripts while also having cultural experts provide context in English as to idioms used that would not have resonated with US team members.

Section summary

- *We assembled a multicultural team of research assistants to serve as cultural experts for the qualitative data collection, transcription and translation*
- *We used a two population sampling framework where we recruited both PLHIV as well as community members in order to understand both self and public stigma in relation to HIV and mental illness*

- *We used both focus groups and in depth interviews for this study, with the focus groups informing an iterative process as to question refinement for the individual interviews*
- *With the large amount of data collected, we created a systematic way of translating and transcribing the data to ensure management and efficient production of transcripts*

Research Practicalities

Teamwork Logistics

Our team primarily included researchers based in Botswana and multiple locations in the US. Our collaboration was centered around a standing weekly conference call. During these calls, we would discuss codes, update the full team on the progress of individual coders, and assign other research-related tasks. Additionally, for coders who were not embedded in Setswana culture, these calls provided a valuable time for obtaining cultural insights from Batswana members of the team. For example, many quotes included figures of speech or important Setswana terms. Having these standing calls allowed coders to flag these phrases for discussion to deepen understanding and strengthen the validity of the analysis. In addition, we would have smaller sub-team calls (usually after the main call) for the PI and subsets of the team working on specific aspects of the project (e.g., drafting the methods section of a manuscript).

Recruitment Procedure

We used a unique sampling method in order to capture as aforementioned both public and internalized stigma. Sampling from both a large public hospital as well as a public square meant we needed a system in place to recruit both types of respondents in a timely fashion to be able to hold focus groups first and then interviews. With the RAs we decided on a schedule of days that we would have at least one RA at each site. Our team decided to hold the focus groups during one week and then have interview times spread across approximately three weeks in order to give respondents ample options to sign up for time slots. During the recruitment process we collected name and phone numbers so that we could contact respondents via text or call to remind them of their interview time.

Consent Procedure

We felt it was best to have the consent procedure be available in both English and Setswana. We also asked for written consent from respondents and therefore had each consent form include English and Setswana text. Following the consent procedure of explaining the study, risks, and benefits we decided to include a five-question consent quiz. We believed this added an extra system of checking understanding about the study especially given the topics being covered and to prevent potential risks or challenges in an individual being uncomfortable once the study began. If on any question the content was re-explained twice and the respondent still did not answer correctly then the respondent was not to proceed in the study. Examples of questions in the quiz are the following:

- The purpose of this study is to (multiple choice)
- If I agree to participate, that means I am agreeing to (multiple choice)

- I can refuse to answer any questions that make me feel uncomfortable (true/false)
- If I agree to participate my care can be affected (true/false)
- The research interview will last (multiple choice)

Ethical considerations

Working collaboratively across different countries (e.g., the US and Botswana) as well as institutions meant complying with multiple ethical considerations. In total, our study went through 5 institutional review boards (IRBs), the University of Botswana, Princess Marina Hospital, the Botswana Ministry of Health, New York University, and the University of Pennsylvania. Even though all research goes through an IRB process, when designing a study that spans different countries, it is important to build in time for the multiple IRBs that need to approve of the study. This can be difficult if one is on a tight timeline for study completion and needs to satisfy many different ethical requirements. In our case, it took approximately eighteen months for all approvals to be obtained. However, all of these were necessary to be welcomed into the various spaces we recruited from as well as to have both US- and Botswana-based review boards help refine the study design to ensure we protected the respondents and data using best practices.

Asking about mental illness and HIV are both sensitive and stigmatizing topics. When working with topics such as these, we felt it was important to frame focus group and interview guides in a manner that started broad and then asked about more individual experiences. For example, we started off with an icebreaker that focused on defining stigma and briefly asked to hear one or two examples if respondents felt comfortable. Then the specific questions of the study started off by asking about “most people”, for example “most people would treat someone with a mental illness just like anyone else”. As respondents felt

more comfortable, more examples would emerge. These focus groups and interviews also took place in private spaces that were largely sectioned off from others at the hospital or community center in which there was little chance of interruption from or being heard by others. Our goal in finding spaces that were safe and private was to protect from labeling and stigma given their agreeing to participate in a study specifically about HIV and mental illness stigma. We also de-identified the transcript data following the interviews by giving each participant an ID number as another way to protect the confidentiality of respondents.

Analysis

Details about the analytic process can be found in the manuscripts reporting on the study (e.g., Becker et al, 2019). Here we will highlight a few key distinctions between the analysis of the HIV stigma portion of the interviews and the mental illness portion.

1. *Inductive vs. Deductive Analysis*: Patterns within qualitative data can be identified in a “top down” (deductive) manner or “bottom up” (inductive) approach. Using an inductive approach, themes are closely linked to the data, and may or may not closely resemble the questions asked. In contrast, deductive analysis may apply some predetermined codes, driven by the researcher’s theoretical framework and a review of the literature, with the aim of answering more specific research questions (Braun & Clarke, 2006). For the HIV analysis, a predetermined theory (WMM) and a literature review of culture in Botswana were applied, so a primarily deductive coding approach was used. In contrast, the mental illness section was exploratory, with less emphasis on predetermined theory, so we used thematic analysis, an inductive approach. Thematic analysis is relatively quick and flexible, enables

generation of unanticipated insights, and is an accessible method for researchers who have limited experience conducting qualitative analysis (Braun & Clarke, 2006).

2. *Large coding team vs. predominantly single coder:* Qualitative researchers have argued the merits of both utilizing coding teams and taking a single coder approach (Bradley et al, 2007). For the HIV analysis, we assembled a team of four pairs of coders, with supervision from the study PI. Each pair double-coded $\frac{1}{4}$ of the transcripts, which were discussed between pairs and with the full team weekly. This allowed for a high amount of rigor (e.g., stability of code application over time, reproducibility of coding) and numerous perspectives on the data (as words may have different meanings to different people and in different contexts), but required a considerable time commitment (two hours/week for eighteen months among eight people). In contrast, for the mental illness analysis, a single coder analyzed each transcript, with a smaller coding team (three others) helping to develop the codebook and double-coding one-third of the transcripts to ensure reliability and stability of the codebook. Campbell and colleagues (2013) examine considerations for conducting analysis with the approach. Using the single coder approach, the entirety of data was coded in approximately four weeks (with the single coder working full-time on the study). We used the single coder approach primarily due to time constraints of the rest of the team. This approach can be useful for others who do not have access to collaborators to assist with coding.
3. *Coding with Microsoft Word vs. NVivo:* Several software packages (e.g., NVivo, Atlas.ti) have been developed to facilitate analysis of qualitative data.

These packages can help organize and sort data, compare data, and calculate inter-rater reliability. Some of these packages are expensive, although free versions also exist, but all require some time and training to learn. To learn NVivo, we used guides produced by experienced researchers at our institution's mixed methods lab as well as videos online and troubleshooting forums on the software's website. For the mental illness analysis, which was predominantly conducted by a single coder, NVivo was used and enabled a relatively quick and efficient analysis. For the larger team, it would have been costly to purchase NVivo for everyone and train all coders in its use. Instead, we used the comments feature in Microsoft Word to highlight and code passages of text. Next, we started a shared spreadsheet with columns of key codes, and teams added quotations from their transcripts to the spreadsheet. The latter approach was accessible and easier to learn, but resulted in analysis of coded data that was more time consuming than the NVivo approach.

Section summary

- *Our team spanned two countries as well as cultures and use of weekly standing conference calls with all team members was important in continuously capturing the key cultural as well as analytical aspects necessary for this study*
- *We detail here the two step sampling process in order to have respondents who are PLHIV or from the community*
- *There are various ethical considerations to address when working with sensitive study topics including asking questions in a safe and comfortable manner in addition to*

having to work with a number of institutional review boards given the multi-country team

- *We highlight differences in coding methods (inductive/deductive), number of coders involved (individual/pair or team), and software used (qualitative data analysis software/word processing and spreadsheet) between our larger HIV stigma study and that of the mental illness study*

Method in Action

Depth and Breadth of Data

As aforementioned, we had a considerably large qualitative study. In addition, and of equal importance, all focus groups and the vast majority of interviews yielded nuanced, in depth responses about our topics of interest. We believe there are a few reasons for the ease of obtaining these rich responses that ultimately led to quality data for our study. First, respondents were given a choice as to whether they wanted to participate in a focus group or interview. During recruitment, we would explain the difference in each method and then respondents would be enrolled based on their preference. Second, we also gave them a choice as to language they wanted to use during interviews. We believe both of these options set a respectful tone, allowing respondents agency in how they worked with us in the study. These were in addition to using the “most people” questions at the start of interviews. Various results in our study are from respondents discussing people they know and many were comfortable responding to probes such as us asking them to provide examples of stigmatizing experiences or instances when they saw others be affected by stigma.

Transcription and Translation Issues

We completed our study in a context with limited prior qualitative research and therefore did not have experienced research staff available to translate and transcribe the interviews prior to hiring our RAs. It is important not to underestimate the difficulty and time demands of translation and transcription. When we began coding, we found the transcripts were briefer and less detailed than we recalled from the live interviews themselves. A bilingual member of the research team subsequently began comparing recordings to transcripts to ensure that the transcripts were capturing appropriate level of detail. Unfortunately, despite efforts at retraining, we did not find the transcripts were consistently meeting quality standards until hiring a fourth translator. Her hard work and dedication to the research goals have resulted in her remaining an integral member of the research team years later. Paying translators by the hour also rather than by the transcript may make study costs less predictable but may create working conditions that encourage high quality transcripts.

Writing the manuscript

Once data analysis was completed, we outlined and drafted the manuscript. As a guide for what information to report, we referred to a review by O'Brien and colleagues (2014) of standards for writing qualitative manuscripts. The paper provides a useful guide for essential information that should be included in every section of the paper (e.g., title, abstract, methods and discussion) in order to demonstrate rigor. The lead author would draft one section per week, flagging points that needed clarification from different team members

(e.g., cultural experts) and then we would review the section as a team over a conference call in order to refine the section.

Section summary

- *We were able to collect a large amount of qualitative data and believe the choice of focus group or interview, as well as language preference helped in having this result.*
- *To obtain high quality data, constant checking and in some instances the retraining and/or hiring of new staff is necessary to ensure translation and transcription is completed accurately.*
- *The writing of the mental illness manuscript came together through leadership by the primary author, the use of a seminal paper for qualitative methods, and through continuous communication with the cultural experts.*

Practical Lessons Learned

We learned a variety of practical lessons through our work on this team-based, multi-cultural qualitative study, particularly regarding study expectations and data management. First, we felt that engagement well in advance of being on the site to detail day-to-day operations and practicalities was important in anticipating the needs of the study. While challenges came up during the study, having an established team and knowing the right resources and individuals to communicate with to quickly solve problems made a difference in preventing derailment of the study. In addition, a clear division of responsibilities also enabled us to have a well-defined and organized study. While all studies have principal investigators, the use of cultural experts (e.g., both local researchers and RAs) meant a

number of individuals with leadership capacity to keep the study moving forward. Diffusion of responsibility meant that the study leadership, inclusive of local researchers, largely set the study objectives and then RAs had agency and were responsible for subsets of interviews conducted and transcripts that stemmed from these.

We also found that when recruiting it is necessary to set a budget if a study plans to compensate respondents. The study must be clear about what the compensation is meant to cover. Compensating respondents for their time is useful for showing respect for respondents yet must not be coercive or appear to be paying respondents to participate. Therefore, we provided compensation for transportation costs only as this was typical of other studies in this setting.

We encountered practical difficulties managing a large amount of qualitative data. Our transcript file names were labeled according to the file names created by our audio recorders, resulting in file labels such as “IDI A2 REC009 - 2017 06 15 INTERVIEW ONLY - Rec 2.” Once we started using these names, it was hard to change them, as other data (e.g., participant demographics) and coder assignments quickly became linked to them. Such complicated file labels proved confusing to work with, and, in the future, re-labeling files early in the research process with simpler more plain language titles, such as “Clinic Male 1” will make for easier data management.

Finally, having a multi-method study (e.g., focus group and interviews) allowed for capturing both saliency and in depth examples for our research topics of interest and it was necessary to consider best practices and methods when working with vulnerable populations such as PLHIV. Since we were studying stigma in particular and specifically its association with two stigmatized conditions, HIV and mental illness, incorporating different methods

(focus groups and interviews) and languages (English and Setswana) to help respondents feel at ease worked very well in our study.

Section Summary

- *Having clear communication from the start of the study though the analysis is key to anticipate potential challenges as well as understand the ways teams can troubleshoot them*
- *It is important to consider best practices to manage respondent recruitment such as compensation methods and giving respondents options for participation*
- *Use of multiple methods for a qualitative study can provide rich results especially when working with an inclusive and well trained team where agency is given to all team members to contribute highly to the entire study*

Conclusion

The purpose of this case study was to detail the use of qualitative methods, both focus groups and in-depth interviews, to study HIV and mental illness stigma in Gaborone, Botswana. A large part of conducting exploratory work in another country is considering the cultural knowledge that is necessary to properly ask research questions as well as understand the data. In addition, designing questions to orient participants as well as enable comfortable settings for questions to be asked we feel are integral to these types of studies. Of equal importance, the use of these methods with the inclusion of cultural experts made for a wealth of information generated from our questions. We hope through

our case study that future studies can draw from our qualitative lessons to advance areas of research.

Section Summary

- *This case study reviewed interview and focus group methods used to investigate stigma in Botswana.*
- *We reflected on our use of cultural experts and methods of asking questions about sensitive topics, illustrating approaches that may be useful for others conducting similar studies*

Classroom Discussion Questions

1. If you were planning a qualitative study in a developing setting, what would be three considerations you would want to think about beforehand on how to conduct the study?
2. What were the merits of having cultural experts on the team for the study?
3. What is the importance of considering double-coding of transcripts when using focus groups or individual interviews?
4. What are some of the ways in which a study team can design focus group and interview guides to ask sensitive questions to respondents?

Multiple Choice Quiz Questions

1. **Who were the team members involved in data collection?**

- a. Cultural experts
 - b. Research Assistants
 - c. The principal investigator
 - d. All of the above [CORRECT]
2. Which of the following is *not* a reason for using focus groups?
- a. Capturing cultural saliency
 - b. Informing in-depth interview guides
 - c. Providing an alternative to one-on-one interviewing for respondents
 - d. Protecting a participant's privacy and anonymity [CORRECT]
3. Which of the following is *not* an advantage of thematic analysis?
- a) Easy to learn for relatively inexperienced qualitative researchers
 - b) Enables generation of unanticipated insights
 - c) Ideal for application of predetermined codes identified from existing literature [CORRECT]
 - d) Usefully summarizes important features of a large body of data
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Declaration of Conflicting Interests

The authors declare that there are no conflicts of interest.

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Further Reading

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