Who’s doing alright? Mental health and well-being of lesbian, gay, bisexual, transgender and intersex people in Southern and East Africa

RESEARCH REPORT FROM A COLLABORATIVE STUDY IN 9 COUNTRIES

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**B) Methodology**

This section described how we conducted the study.

**Participatory approach**

For this study, we followed a community-based participatory research (CBPR) approach. Community-based research is a partnership approach to research that involves community members and academic researchers as equal partners in all stages of the research process. In this way, all partners can contribute their knowledge and skills, can decide jointly on what to research, how to do it, and what to do with the research findings. It also means that all partners share the responsibility and the ownership of the process and the research findings (Israel et al., 1998).

CBPR is a well-used approach for studies that explore health-related disparities, particularly among marginalised communities, such as people of colour, or people living in poverty in the US (Israel et al., 2010). Because it directly involves communities as co-researchers, it is an excellent approach to examine the social context of health concerns (Leung, Yen and Minkler, 2004). Because it emphasises that power is shared between researchers and the community, and because it focuses on action based on the research findings, it also helps to ameliorate the understandable distrust of academic research that often exists among marginalised communities (Israel et al., 2010).

There were 21 community partner organisations for this study. The academic partner was the Gender Health and Justice Research Unit at the University of Cape Town in South Africa. Additional academic partners were Dr Chelsea Morroni from the University of Botswana; Prof Adamson Moola from the College of Medicine, University of Malawi; Sindy Matse from the National AIDS Council in the Ministry of Health of Swaziland and Nelson Muparamoto from the University of Zimbabwe. The project was funded by COC Netherlands, who also provided logistical support throughout the process.

**Study design**

In October 2015, COC Netherlands held a consultative meeting with the community partner organisations and researchers from the Gender Health and Justice Research Unit (GHJRU). At that meeting, partner organisations identified the gaps in current research and knowledge on LGBTI people’s health in the Southern and East African region. Additionally, the partner organisations, GHJRU researchers and COC discussed what study design would be best suited and discussed strategies for sampling and recruitment. These discussions identified a number of areas where more research is needed to better understand LGBTI health concerns. To address all of these areas was beyond the scope of this research project. We ranked all research needs that were identified and decided to focus on the top three: mental health and well-being, experiences of violence, and access to healthcare services.

Based on the discussions with the partner organisations, we (the GHJRU researchers) developed the study design. After all community partners, as well as COC Netherlands, provided feedback our suggestions, we finalised the study protocol and developed the survey. Because there is currently little or even no research evidence on LGBTI people’s mental health and well-being in our Southern and East African context, this project is an important opportunity to develop baseline data. For this reason, we developed a survey that could be used in all study countries, in order to compare findings across countries.

**The survey**

We reviewed national and international academic literature on how to measure mental health and well-being amongst LGBTI populations, specifically in Southern and East Africa. Based on these findings, we developed a draft for the survey we wanted to use in the study. We held two meetings with the community partner organisations and COC Netherlands to discuss the scope, questions and wording of questions in the survey, and we revised the draft based on the feedback we received.

In each meeting, we held a group session to review the survey question by question and adjust the aims and wording of each section and question. As a team, we agreed to make small changes to standardised scales that measure mental health outcomes. While we wanted to create a single survey that could be used in all countries, in some instances we changed the wording of some of the questions for specific countries, so that participants would understand them better (for example, “apartment” versus “flat” or “room”).

Once we had done all the suggested changes, we sent the survey to all community partner organisations and COC for a final round of feedback. Based on this last feedback, we finalised the survey.

**Question design and data cleaning**

All questions on the survey had categorical answers (answers that would group participants into groups, for example people who lived in Botswana, people who lived in Kenya, people who lived in South Africa, etc.). Only age, and number of cigarettes smoked per day were measured as continuous variables (information that can be measured on a scale or counted).

For many questions, we added an “Other, specify” option, so that participants could write or type additional/different information. When we cleaned the data, and entered it into our database, we examined and re-coded the answers to these “other” responses into other categorical options, as appropriate.

**Conflicting data**

In some instances, questions were asked about the same experience twice: first about the experience in participants’ lifetime, then in the last 12 months. For example: 301. Has there ever been a period of time when you thought about committing suicide? a. In your lifetime? 1 Yes 0 No b. In the last 12 months? 1 Yes 0 No

In some instances, participants entered a conflicting response; for example, saying that they had not thought about suicide in their lifetime, but had thought about it in the last 12 months. In some instances, they left the question about lifetime incomplete, but said they had thought about suicide in the last 12 months. During data cleaning, we made the decision to recode “lifetime” as “yes” in these instances – so if a participant said they had experienced something in the past 12 months, by default they had also experienced it in their lifetime. This was done for all questions in the above format in the questionnaire.

**Demographic measurement**

We asked a number of questions to learn about participants’ socio-demographic circumstances. These included age, religion, education, housing, employment, race, and financial security (assessed by the question “On average do you have enough money to cover your basic needs?”).

*Sexual orientation and gender identity measurement*

In public health literature, there is no recognised standard definition of sexual orientation. Sexual orientation is widely accepted as being comprised of three elements: sexual identity, sexual attraction, and sexual activity. A range of studies have used different combinations of these three elements to define participants’ sexual orientation (King et al., 2008). In order to paint a nuanced picture of the participants’ sexual orientation, we aimed to assess each of these three elements.

1. Sexual identity was assessed by asking participants “In terms of your sexual orientation, how do you identify?” (Options: Lesbian, Bisexual, Gay, Heterosexual, Asexual, Other specify)
2. Attraction was assessed by asking participants who they were sexually and emotionally attracted to (2 questions).
3. Sexual activity was assessed by asking participants about who they have had “sexual experiences with in the past year and their lifetime” (2 questions).

For attraction and sexual activity, the questionnaire gave participants a list of options from which they could select all that applied (Options: With women, with men, with trans women, with trans men, with gender non-conforming people, with intersex people, “I have not had sexual experiences”, Other specify).

There is also no standardised way of asking participants about gender identity. We decided to combine two questions: 1) Gender identity was assessed by asking “In terms of your gender identity, how do you identify?” (Options: Woman, Man, Trans woman, Trans man, Gender non-conforming, Other specify). 2) We asked about sex assigned at birth (Options: Male, Female, Intersex)

3) Additionally, we asked what sex/ gender was recorded in the participant’s identity document(s)

We asked about self-stigma experiences by three groups: (1) sexual minorities (for the purposes of this scale, sexual minorities were those who are not heterosexual or asexual) (2) gender minorities (those who identified as transgender, gender non-conforming, or gender queer and (3) participants with diverse sex characteristics (identifying as intersex). To measure self-stigma, we adapted Likert scale measurements that had been used in other research with sexual minority people (Meyer, 1995; Pinel, 1999; Frost and Meyer, 2009; Herek, Gillis and Cogan, 2009).

*Violence measurement*

We developed the questions that asked about experiences of violence based on the GHJRU’s previous work in violence research. Additionally, we reviewed literature about intimate partner violence among LGBTI people (Calton, Cattaneo and Gebhard, 2015). We asked a series of “yes/no” questions about experiences with verbal harassment, emotional violence, physical violence (“Have you been physically assaulted?”), and sexual violence (“Have you been sexually assaulted?”). For physical and sexual violence, we asked about experiences in the last 12 months and in participants’ lifetime. For those who experienced violence, we asked additional questions about access to related-health services. We asked about three signs of post-traumatic stress: flashbacks; avoidance; and feelings of jumpiness, irritability, or restlessness. We created a binary variable for signs of post-traumatic stress: those who showed all three signs were categorised as having signs of post-traumatic stress; those who showed one, two, or no signs were categorised as not having signs of post-traumatic stress. This binary variable was used when post-traumatic stress was included as a co-variate in logistic regression models.

*Translations*

The survey was translated into the following languages: Chichewa, isiNdebele, Sesotho, Setswana, Shona, Siswati and Swahili. These translations were done by professional translators, and then reviewed by the community partner organisations. The changes that the partner organisations suggested were then discussed with the professional translator, and incorporated into the final translated versions.

*Fieldworker training*

Each community partner organisation had a designated research coordinator, and a research assistant. These two were responsible for training and overseeing fieldworkers, who collected data by handing out surveys to participants. We (the GHJRU researchers) trained the research coordinators and assistants in a three day ‘Train the trainer workshop’. The training included information on research processes, how to make decisions about study design and methodology, best practices in data collection, research ethics and participant protection, as well as discussions about data analysis and the use of data once the study is over. We wrote a fieldworker manual, so that research coordinators and assistants would always have access to the information from the training. When organisations decided to employ additional fieldworkers, these were trained by the research coordinator.

*Eligibility to participate*

Eligibility to participate in the survey was defined by age, sexual orientation, and gender identity.

* Be of adult age: all participants needed to self-identify as being age 18 or older
* Self-identified as LGBTI: Participants were required either not identify as heterosexual (and therefore be a sexual minority/member of the LGBTI community) or not be cisgender (and therefore be a gender minority, for example, transgender). Included in gender minorities are people with diverse sex characteristics (or who identified as intersex). We asked participants to self-identify. In the informed consent statement, we gave the following prompts to help potential participants determine their eligibility: gay, lesbian, bisexual, transgender, transsexual, transman, transwoman, intersex, queer, genderqueer, gender non-conforming, pansexual, omnisexual, men who have sex with men (MSM), women who have sex with women (WSW), kuchu.

Our study did not use a comparison group—that is, we did not survey people who were or identify strictly as heterosexual and cisgender. While this limits our ability to compare our findings about sexual and gender minority people with heterosexual and cisgender people, we draw on research with the general population to discuss possible differences between LGBTI people and heterosexual, cisgender people.

*Sampling methodology*

Decisions around sampling for LGBTI populations are complex, and impacted by a number of factors unique to this population and the specific country-context. Sampling is complicated by the following factors, as described by Meyer and Wilson (Meyer and Wilson, 2009):

• LGBTI populations are not easy to identify. Sexual orientation and gender identity are not fixed constructs, different people have different identities, and this is particularly important in contexts where Western concepts of L, G, B, T and I might not hold the same value for everybody.

* LGBTI populations are hidden. For a sampling method that predicts larger, population-size trends, researchers need to know the overall population size, in our example, the overall number of LGBTI individuals in each country. This of course is impossible to determine, both because of the previous point, and because sexual orientation and gender identity are not registered in national census data, thus making impossible to obtain this information. This means that sampling methods that will allow us to make predictions about ALL LGBTI people in a certain context are impossible at this moment.
* Given that many partner organisations do not have definite numbers of their constituency population, it will be impossible for us to even make generalising predictions about any organisations’ constituency population, for the same reasons outlined in the previous point (Meyer & Wilson, 2009).

Given these restrictions, we combined two sampling methods: community-based sampling and online-based sampling. We chose to combine these two sampling methods for two reasons:

* Hendricks and Testa (Hendricks and Testa, 2012) show that needs assessments and community-based samples, such as the one we used for our study, often reach especially vulnerable parts of sexual and gender minority populations. This means that the people who participate in community-based surveys, such as ours, are often disadvantaged in more than one way, and so face oppression on more than one level. This means that what we learn from community-based sampled studies can illustrate minority stress by reaching those who are most affected.
* However, Rosser and colleagues (Rosser et al., 2007) have pointed out the limitations of community sampling, which may over-represent targeted problems. In our sample, this means that by sampling people who already access NGOs (arguably because they feel they need support), we might over-estimate the level of mental health problems among sexual and gender minority people more generally. Therefore, we have added online-based sampling to also reach people who do not access NGO services directly.

Neither of these two sampling methods allow us to draw inferences beyond the constituency population, meaning we will not be able to make predictions about larger LGBTI populations across the country or region. The findings from our study are therefore not representative of all LGBTI people in the participating countries.

**Data collection**

As part of the participatory design of this project, each partner organisation designed an individual plan for recruiting participants, based on the recruitment plan that we have explained above. Organisations used a range of methods, including: promotion of the online survey through a facebook advert, promoting the survey among people who came for services at their office, recruiting through personal and professional networks of the fieldworkers.

The partner organisations used a mix of self-administration and fieldworker-administration to collect the data. Self-administration meant that the participant read the survey to themselves and filled it out on their own. Fieldworker-administration meant that a fieldworker read the questions to the participant.

**Pilot study**

Before finalising the questionnaire, we conducted a pilot study in South Africa, the first country to implement data collection. The purpose of the pilot was to identify questions that should be added or removed, rephrased, or otherwise adjusted. The pilot study showed us a few questions that we needed to change in order to make the survey as easy to understand as possible. Once we made these changes, the questionnaire was considered final. We made no more changes to it during the study.

**Data analysis**

We entered all survey data into a REDCap database, and then analysed it with the software Stata15. We ran descriptive statistics and measured associations between differences that we found among the participants in our sample. Where data was missing because participants had not answered a question, we used a method called ‘multiple imputation’.

For many key outcomes in this report, we sometimes report statistics for subgroups of the overall sample. We use this approach to highlight times when specific subgroups may be particularly vulnerable due to historical and persistent socio-economic disparities and oppression. However, we also chose to do this only in countries where the size of the overall sample and subgroup were large enough to examine meaningfully. For example, in South Africa we examined differences between Black and White participants (due to historical disadvantages of Black South Africans) and between gender minority and cisgender participants.

**Research approvals and regulatory compliance**

Our study was approved by the University of Cape Town’s Faculty of Health Sciences Human Research Ethics Committee. Additionally, we sought permission to conduct this study through national approval processes in the countries outside of South Africa.