Communicative Competence for Researchers working with LGBTQ Communities

Jesica Pagano-Therrien, PhD, RN, CPNP[1], Germán Chiriboga, MPH[2], Shauna Simpson, MS[2], Joanne Calista, MS, LICSW[3], & Kendra Marien, MSW, LICSW[3]

[1]UMass Medical School, Graduate School of Nursing, Worcester, MA; [2]UMass Medical School, Population and Quantitative Health Sciences, Worcester MA; [3]Center for Health Impact, Worcester, MA

INTRODUCTION

- The ethical principles of **respect** and **justice** oblige the use of culturally sensitive approaches when engaging participants in research.
- Cultural competence training is lacking for researchers and research staff who work with lesbian, gay, bisexual, transgender and queer (LGBTQ) populations.
- This study explored how researchers and research staff can foster a welcoming and trusting research environment for LGBTQ research participants in the context of underlying distrust of medical and research settings as a barrier to both healthcare and research among minority populations.
- Grounded by a framework of **communicative competence**, this study explored elements of preferred communication to be used during recruitment and informed consent for research involving LGBTQ participants.

PURPOSE and AIMS

- The purpose of this study was to develop community informed guidelines identifying important elements of verbal and non-verbal communication to be used in the context of recruitment and informed consent for research so that researchers and research staff can create a trusting and welcoming research environment for LGBTQ research participants.
- Specifically, this study aimed to:
    1. Identify words, expressions, and non-verbal behaviors to be used or avoided when engaging LGBTQ individuals in research (grammatical and sociolinguistic competence); and
    2. Understand barriers to research for LGBTQ populations and identify strategies to more effectively engage LGBTQ participants in research (strategic and discourse competence).

These guidelines will lay the foundation for the development of a simulation-based, community-engaged communicative competency training program for researchers and research staff.[1]

METHODS

Design, sample and setting.

- Focus groups[2] and individual interviews[3]
- Qualitative descriptive approach[4]
- Participants were recruited by our community agency partner, the Center for Health Impact (CHI) in Worcester, MA.
- Inclusion criteria: 18 years of age or older; identify as lesbian, gay, bisexual, transgender, queer, or as an ally; English-speaking; and willing and able to provide informed consent.
- Exclusion criteria: Adults unable to consent; individuals with cognitive impairment; individuals who were not yet adults; non-English speaking adults; and prisoners.

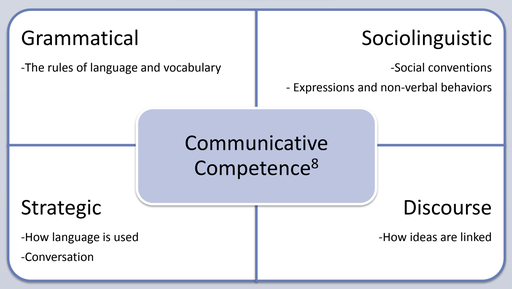
Procedures.

- Waiver of documentation of informed consent; approved by UMMS IRB.
- Recruitment took place between May and December 2018.
- Participants also completed a basic demography form.
- A gift card was provided to participants as a token of appreciation.

Data collection and analysis.

- A semi-structured guide with open-ended questions and prompts guided focus groups and interviews.
- Discussions were digitally audio recorded and transcribed verbatim.
- Qualitative Content Analysis[5] was used to analyze transcripts.
- Coding was managed using MAXQDA Analytics Pro.[6]
- SPSS[7] version 25 was used to manage demographics information.
- Trustworthiness was ensured through peer debriefing meetings, member checks (ongoing), and rich description.[3]

FRAMEWORK

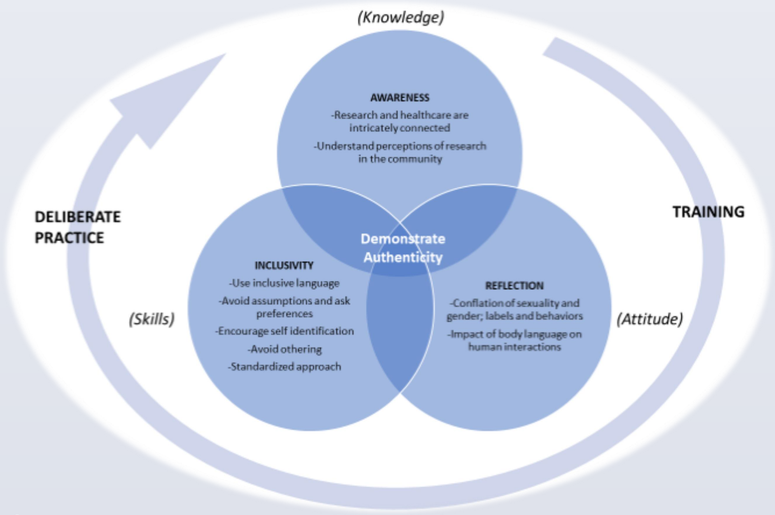


FINDINGS

Participant characteristics. Thirty (30) participants took part in focus groups and 6 took part in individual interviews. Focus groups ranged in size from 3 to 12 participants each. The mean age of participants was 43.2 with a range from 18-80 years. Additional demographic characteristics are listed in Table 1.

Table 1.		Frequency	Percent
Gender	Female	15	41.7
	Male	16	44.4
	Transgender	5	13.9
Sexual orientation	Lesbian	4	11.1
	Gay	14	38.9
	Bisexual	9	25
	Other	1	2.8
	Heterosexual	4	11.1
	Queer	3	8.3
	Not reported	1	2.8
Race	Caucasian	27	75
	Black/African American	3	8.3
	Other race	5	13.9
	Not reported	1	2.8
Ethnicity	Hispanic/Latinx	6	16.7
	Non-Hispanic/Latinx	26	72.2
	Other ethnicity	1	2.8
	Unknown ethnicity	1	2.8
	Not reported	2	5.6

Themes. Findings highlight the need for research professionals working with LGBTQ communities to ***demonstrate authenticity***. Three major themes were identified focusing on ***awareness, reflection*** and ***inclusivity***.



Awareness

- Negative health care experiences may impact willingness to take part in research.
- Researcher professionals must relay open-mindedness and non-judgement.
- Organizational reputation as being LGBTQ-friendly may attract participants.

"It's things as easy as identifying the agency as a pro-LGBT agency or something like that, just getting out there and showing support."

- Research is perceived as valuable to the LGBTQ community, but LGBTQ individuals are felt to be under-represented overall in biomedical research.
- LGBTQ-related studies are often problem-oriented (i.e. substance use) or illness-related (i.e. HIV/AIDS).

"I think in a similar vein, not only is the research…in a sort of negative light, but the research that is usually inclusive of the community is specifically about the community rather than having other research and including queer people in that research. It's specifically about the fact that they're queer and nothing else, and it sort of makes that identity the only identity that's viable to research."

Reflection

- Body language, including eye contact and posture, can demonstrate open-mindedness.

"I think the person needs to look relaxed and kind of an open posture…with your body showing that you are relaxed and that the person is in a listening kind of position…show[ing] that he is listening and paying attention to what I'm saying or the person is saying. For me that's really key. They could be smiling or not, but they are really engaging in the conversation, even if it's a silly or ignorant question or statement that I might be making that they are kind of taking it – versus the body's showing that they're listening and respecting what one is saying."

- Take time to learn and be able to converse in a way shows an understanding that sex & gender, and socially constructed labels & human behavior should not be conflated.

"I do feel like there's a new movement, which is more of gender identity, which includes more of how you identify yourself gender-wise rather than how you identify yourself sexuality-wise, 'cause they're two completely different things. I think that once we've moved from getting more acceptance into sexuality, there's been kind of an openness of trying to get movement towards gender identity. And I feel like that's the confusing part for a lot of people, because it can be confusing. It becomes a big – it's just messy to me, where people don't want to get into understanding it sometimes and… there's a lot to it that I feel like gets in the way for people. They just wanna take the easy road, I think."

Inclusivity

- Choose inclusive language

"Being gender-inclusive to me in language is really, really easy. 'The patient will take off his or her clothes and put on a robe,' where you can replace that with a they, and that's more gender-inclusive. You can replace wife/husband/spouse with just spouse. You can replace 'which gender' with 'what gender' or 'all gender.'"

- Avoid assumptions and ask preferences (may vary by culture and generation)

"Because every person identifies a different way or wants to be referred to a different way, you can't just assume it for any group of people. So if you're not sure, then just ask them."

- Encourage self identification

"…instead of saying, 'Here's your choices,' say, 'How do you describe your sexual orientation? How do you describe your gender?' allowing people to do that rather than having a list."

- Avoid othering

"I feel like I'm put down as other so many times when I fill out surveys... I always have to check off other or just state 'do not wish to respond.' I can't list my sexual orientation, because it's not there. I would have to check off other, and then the same thing with marital status or the gender. I feel like there just aren't categories that fit me."

- Use a standardized approach

"It's not how do we talk to these people, it's changing how you talk to everyone."

RECOMMENDATIONS

- Findings from this study align with existing recommended best practices for providing inclusive services to LGBTQ people.[9]
- Participant perspectives inform a knowledge, attitude, and skills approach to building trust and engagement with the LGBTQ community.
- Findings will guide modifications to the Simulation-based, Community-engaged Research Intervention for Informed Consent Protocol Testing and Training (SCRIIPTT)[1] model which uses community-based trainers to deliver competency training to research professionals.
- New knowledge is practiced using simulation scenarios and deliberate practice followed by feedback.
- Elements of the SCRIIPTT3 training are conceptualized below, with a focus on building grammatical, sociolinguistic, strategic and discourse competence.

- 👍 ***Choose*** inclusive terminology
- 👍 ***Apologize*** if you make a mistake (i.e. use the wrong pronoun)

Instead of…	Try using…
LGBTQ	LGBTQIA+
His or her	They
Husband or wife	Spouse
Man or woman	People
What gender are you?	What is your gender?
A person who is transgender	A transgender person

- 👍 ***Ask*** open ended questions and ensure free-text options (and not simply "other") are provided on questionnaires, surveys, and other forms
- 👍 ***Do*** create a comfortable and welcoming encounter by displaying a relaxed, open-posture, using a calm and reassuring tone of voice, and active listening; staring, stiffening up, breaking eye contact, and awkward silences can convey disrespect and break trust.
- 👍 ***Understand*** diversity and fluidity of expression[9]

Key message for researchers and research staff:
LGBTQ people are people.
"They see themselves as a person and not as a label or identification."
Make an effort to get to know each participant as a unique individual.

SELECT REFERENCES

[1]Nnaji, C., Boone, M., Pugnaire, M. P., Goode, T., Wellman, S., Gunn, A. R., . . . Allison, J. (2018). An Innovative Simulation-based Community-engaged Intervention for Training Research Assistants in Culturally Appropriate Informed Consent. *Prog Community Health Partnersh, 12*(3), 247-262. doi:10.1353/cpr.2018.0049

[2]Krueger, R. A., & Casey, M. A. (2000). *Focus groups : a practical guide for applied research*. Thousand Oaks, Calif.: Sage Publications.

[3]Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.

[4]Willis, D. G., Sullivan-Bolyai, S., Knafl, K., & Cohen, M. Z. (2016). Distinguishing Features and Similarities Between Descriptive Phenomenological and Qualitative Description Research. *Western Journal of Nursing Research, 38*(9), 1185-1204. doi:10.1177/0193945916645499

[5]Miles, M. B., Huberman, A. M., & Saldana, J. (2013). *Qualitative data analysis : An expanded sourcebook* (3rd ed.). Thousand Oaks: Sage Publications.

[6]VERBI Software. (2016). MAXQDA Analytics Pro [Computer Program]. Berlin, Germany: VERBI

[7]IBM Corp. (2017). IBM SPSS Statistics for Windows, Version 25.0. Armonk, New York: IBM Corp.

[8]Rossi, A. L., & Lopez, E. J. (2017). Contextualizing Competence: Language and LGBT-Based Competency in Health Care. *Journal of Homosexuality, 64*(10), 1330-1349. doi:10.1080/00918369.2017.1321361

[9]National LGBT Health Education Center. (N.D.). Providing inclusive services and care for LGBT people: A guide for health care staff. Boston, MA: Fenway Institute.

ACKNOWLEDGEMENTS

Research reported in this publication was supported by the National Center for Advancing Translational Sciences of the National Institutes of Health under award number UL1-TR001453. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH