

What is the lived experience of loneliness in older men living with HIV?

A qualitative analysis to guide service development

Amanda Austin-Keiller, David Lessard, Marianne Harris,
Lesley Fellows, Melissa Park, Nancy Mayo, Marie-Josée Brouillette

10th International Workshop on HIV & Aging 2019

New York, USA

October 10-11, 2019

Oral abstract #15



Conflict of Interest Disclosure

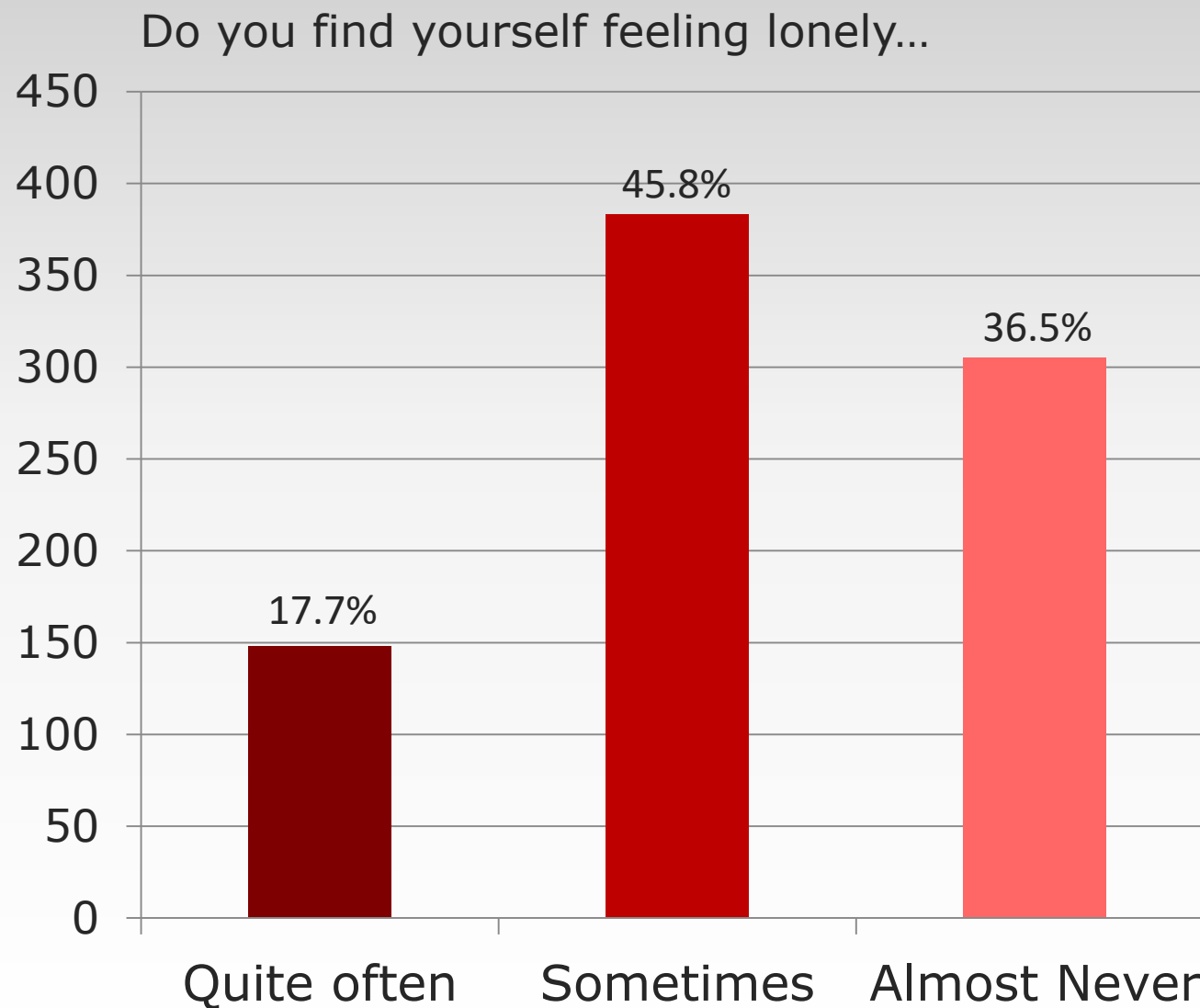
- I have no conflicts of interest to disclose.



Flashback to last year...



63.5% feel sometimes or quite often lonely



5 Canadian Sites
836 responded:
-709 men
-127 women

Model of Loneliness using the Wilson Cleary Model

CONTRIBUTORS

(biological, individual and environment)

Stigma
Fewer than 5 close people
Motivation: No plans/goals
RAND Pain
RAND Vitality
RAND PFI
Not working or volunteering

Loneliness

Hours of physical activity per week
Hours of TV per week
Seldom active
Opioid use
Cognition
Stress
Mental Health

Self-rated
health
HRQoL

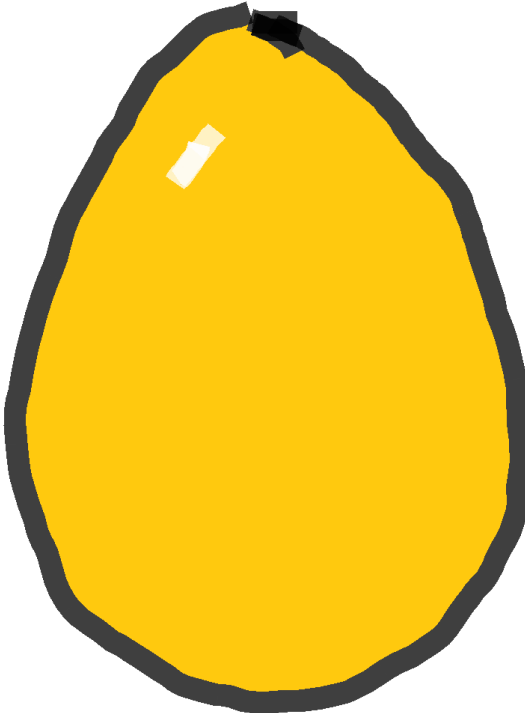
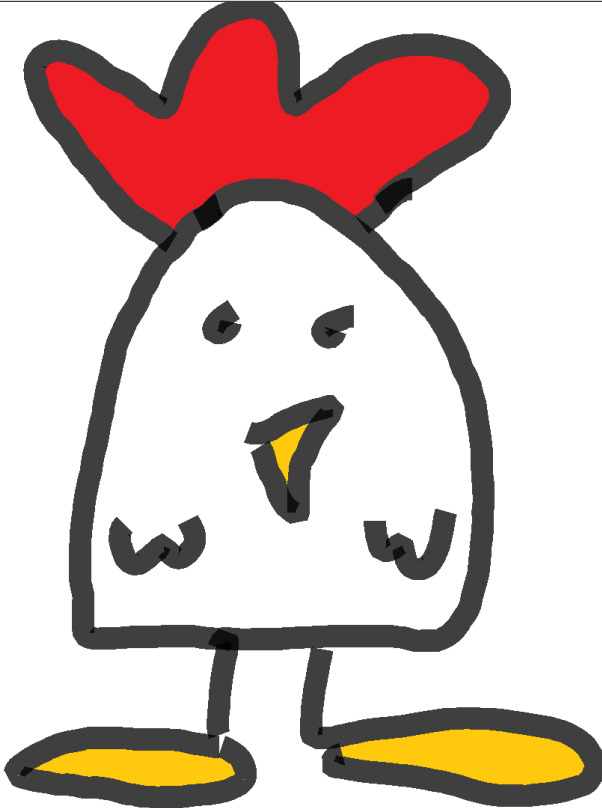
QoL

CONSEQUENCES

Model of Loneliness

(bi

S
F
M
R
R
N

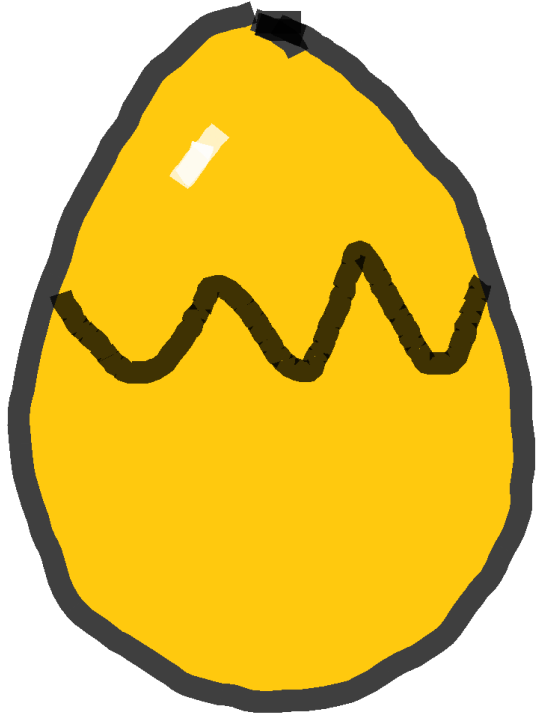
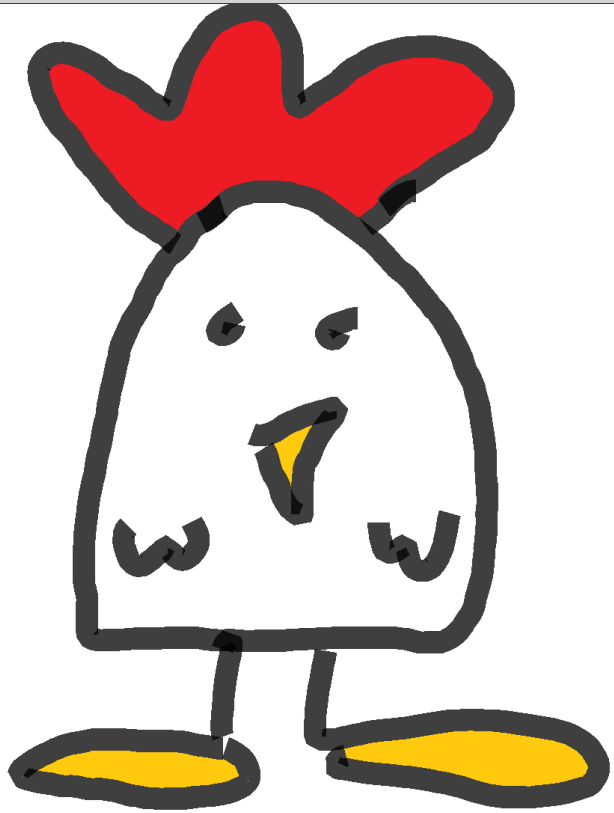


oL

Model of Loneliness

(bi

S
F
M
R
R
N

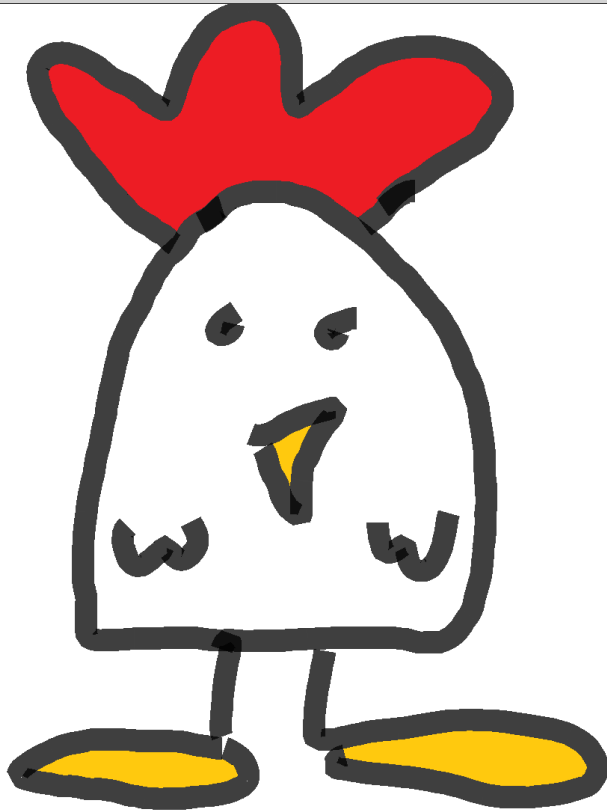


oL

Model of Loneliness


(bi

S
F
M
R
R
N



oL

What is the **experience** of loneliness in older Caucasian men living with HIV in the Montreal area?



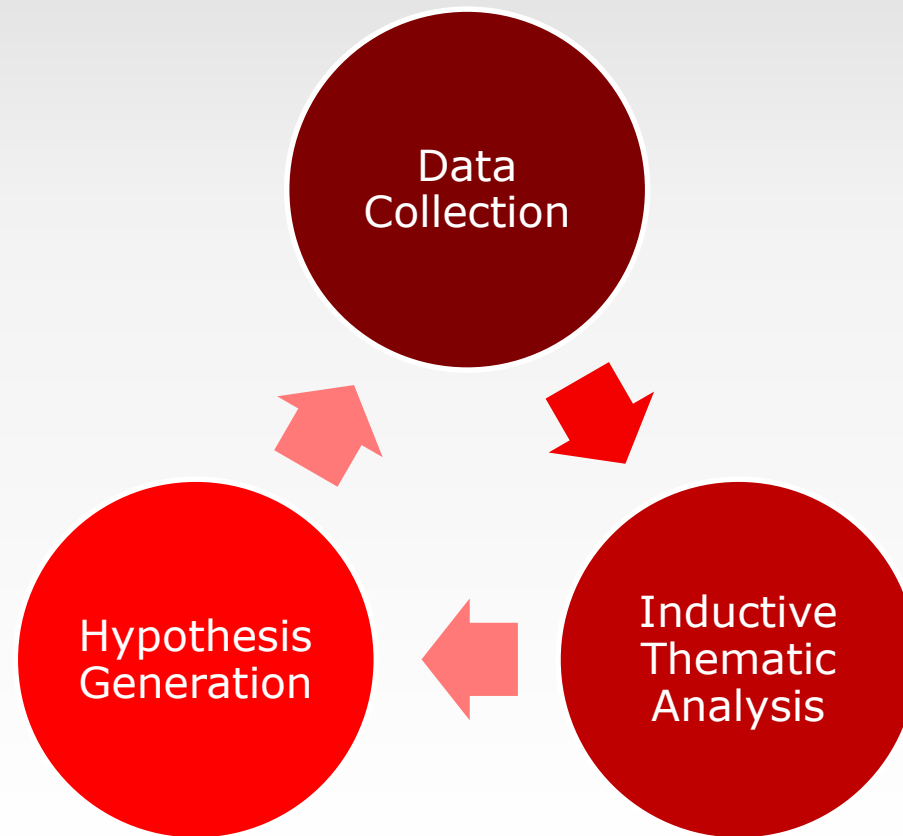
Objectives:

- **Understand contributors and consequences** of loneliness in older men living with HIV as they **experience** them
- **Inform interventions** for psychological and social difficulties in older men living with HIV

Qualitative methods allow for participants' meaningful connections to be understood

□ Theoretical Sampling

- 10 Individual Interviews to elicit personal narratives



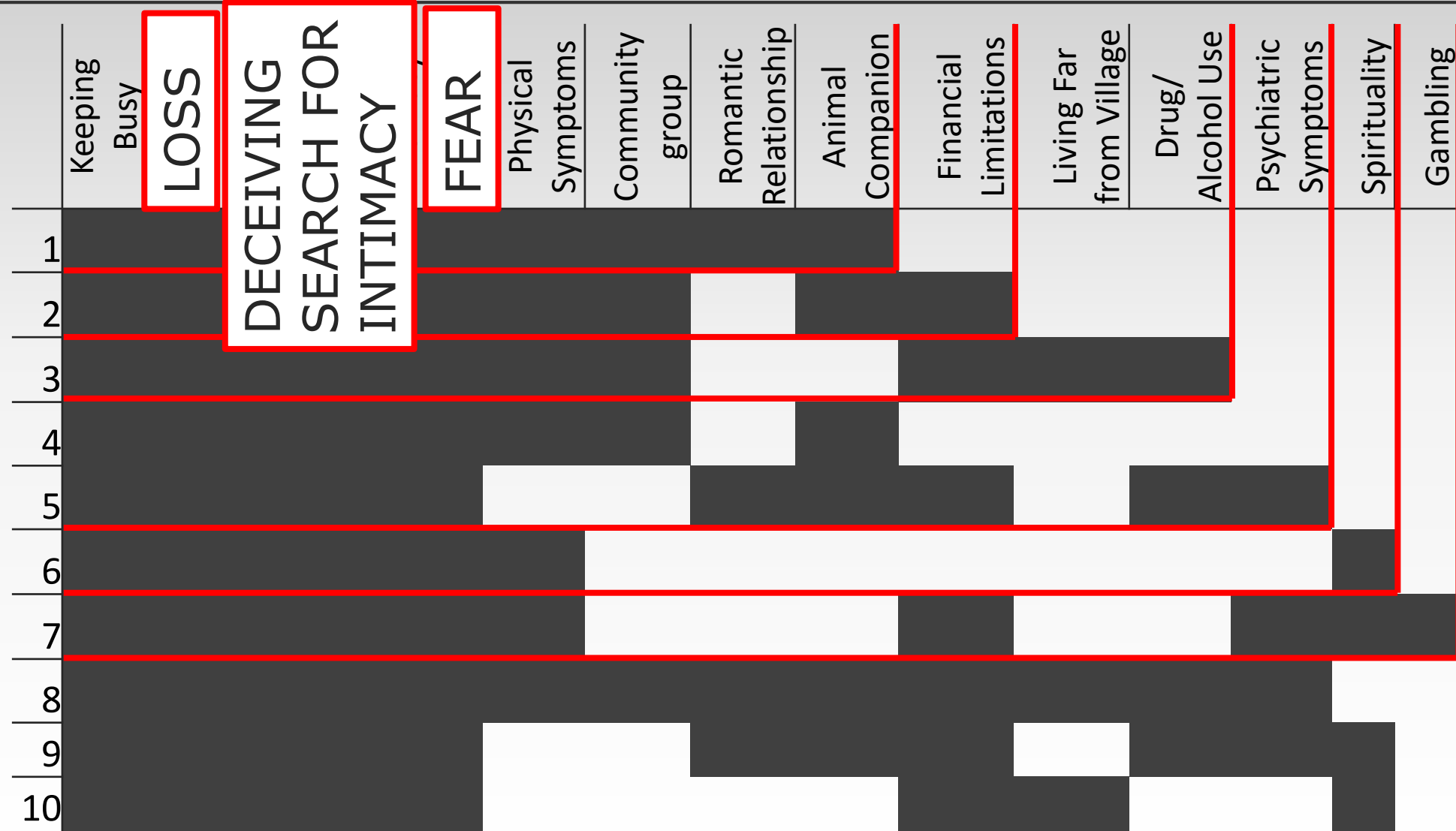
Results



Data Saturation

	Keeping Busy	Loss	Stigma	Deceiving Search for Intimacy	Fear	Physical Symptoms	Community group	Romantic Relationship	Animal Companion	Financial Limitations	Living Far from Village	Drug/Alcohol Use	Psychiatric Symptoms	Spirituality	Gambling
1	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
2	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
3	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
4	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
5	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
6	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
7	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
8	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
9	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
10	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█

Contributors to Loneliness



Contributors to Loneliness

- **Loss**
- A Deceiving Search for Intimacy
- Fear

LOSS

The 5 years after my partner died I felt really alone. I was dealing with the fact that the person that I used to be able to talk to was no longer there. and um. of course that really mixes up your whole life. [...] lots of people that I know have never seen anyone pass away yet. so I was like: 'Wow. I can't even count how many I have lost.'

-Participant A

LOSS

One of my friends, [...] I was always thinking that she was open, open. [...] And one day she called me and said 'oh you [...] I don't want to meet you anymore and eat at the same table I'm going to catch something'.

-Participant G

Contributors to Loneliness

- Loss
- **A Deceiving Search for Intimacy**
- Fear

A Deceiving Search for Intimacy

There is a lack of information. And as soon as you say seropositive, undetectable. Its well he is going to die soon. So finding a friend. Well forget that. [...] On the gay meeting sites. Uhh when you pass the age of 50-60 years old. We forget about it.

-Participant D (translated from French)

A Deceiving Search for Intimacy

It was really deceiving. And for the internet, often on the sites or apps they are whining so much you know. The discussion are never ending and finally **its just for the now**. Or sometimes we plan a date and then two days later they cancel. **There can be a lot of frustration for people with these application**. Dealing with loneliness in that way.

-Participant F (translated from French)

Contributors to Loneliness

- Loss
- A Deceiving Search for Intimacy
- **Fear**

Fear

Its loss. A lot of loss. Of, of people who were important in my life either physically by not being there or having to change. Or something. So ya. Its true. I. I don't. It affects my. My willingness to. Participate or contact or be more social. because I am not.

-Participant B

Fear

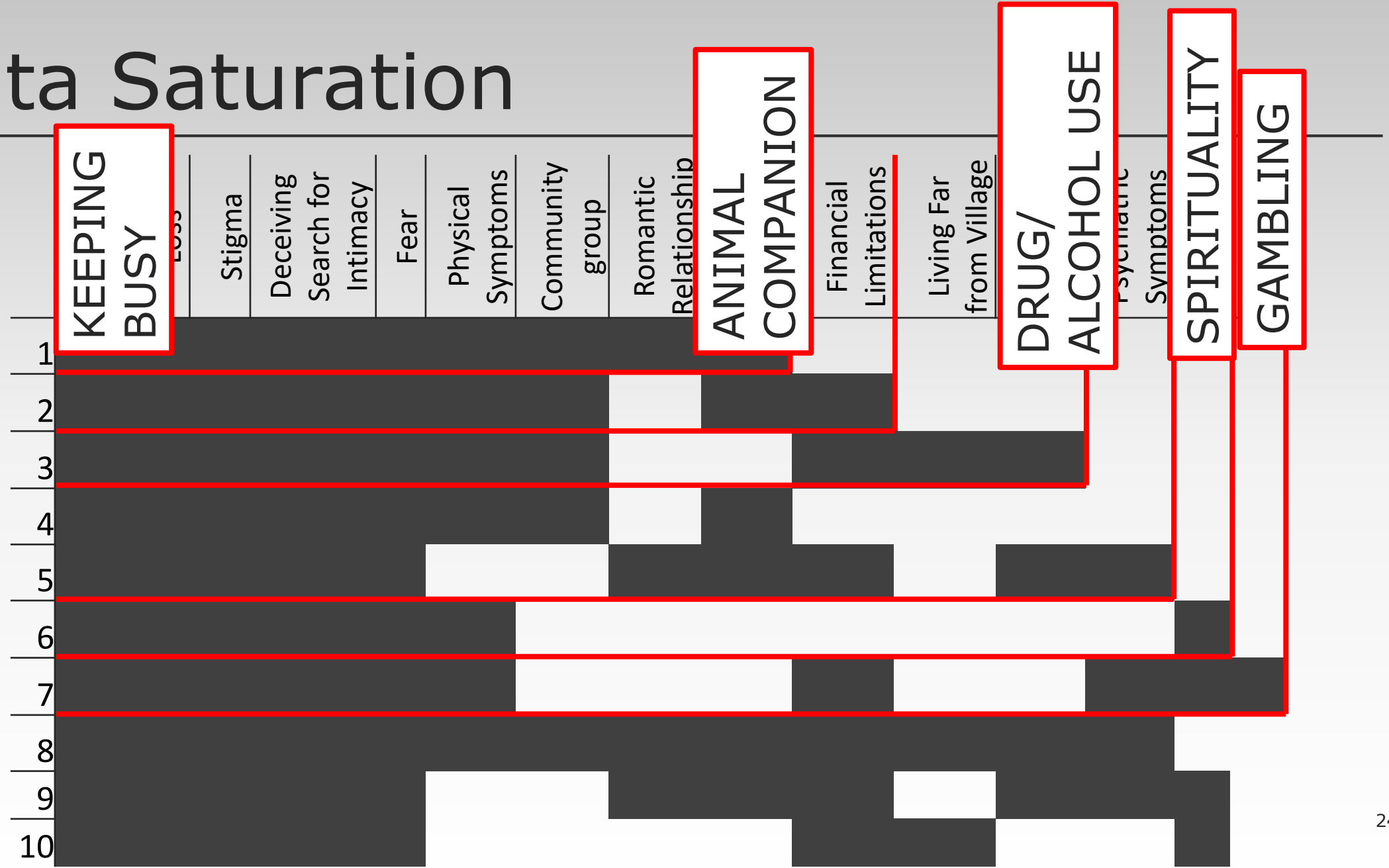
But the loneliness, also. I might have created it. Because I don't open myself up to everybody. **But its because I have had bad experiences.** I have decided to keep a distance from others. [...] I also kept a distance because of [...] **My lipodystrophy.** [...] Today I am not sure what they think but in that era **they knew automatically what you were.** People looked at you on the metro and its. Well it hurts. **Its really hurtful.**

-Participant E (translated from French)

Now what?



Data Saturation



Living with Loneliness

Keeping Busy (work, hobbies, socializing, chores, etc.)	Alcohol
Believing in something bigger than you	Drugs
Animal companion	Gambling

Service Development

- General Community
 - Homophobia, HIV stigma
- LGBTQ+ Community
 - HIV stigma, age stigma
- HIV+ Community
 - Limited group with many challenges

Need social groups that are explicitly inclusive for older LGBTQ+ and HIV+ individuals

Service Development

- General Community
 - Homophobia, HIV stigma
- LGBTQ+ Community
 - HIV stigma, age stigma
- HIV+ Community
 - Limited group with many challenges

?

Service Development

- General Community
 - Homophobia, HIV stigma
- LGBTQ+ Community
 - HIV stigma, age stigma
- HIV+ Community
 - Limited group with many challenges

Need to be more inclusive at a societal level

Take Home Messages

- Keep loneliness on your radar
- Encourage positive self-management
- Resource referral for socializing and improving self-esteem
- **Need Advocacy**

Acknowledgements

- The participants of the Positive Brain Health Now cohort
- Co-authors and colleagues
- Research Assistants
 - Fernando Gonzales Aste
 - Melissa Vu



Thank you

Questions?



amanda.austin-keiller@mail.mcgill.ca