

Exploring the Experience of Mental Health Care Access among Neurodivergent Older Adults: Development of the Interview Guide

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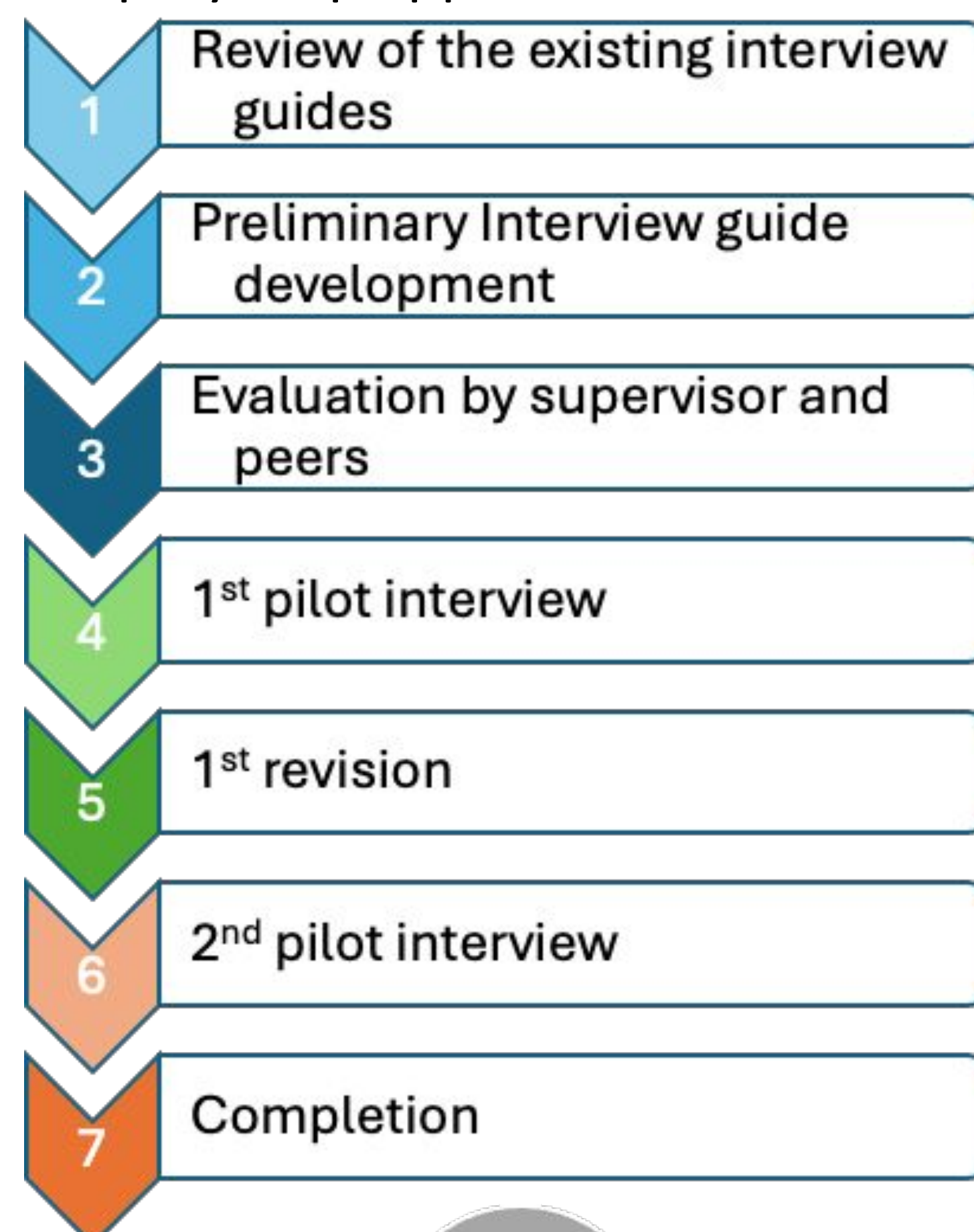


Abstract

The life expectancy gap between neurodivergent and neurotypical individuals is striking, with some studies indicating neurodivergent individuals may live as little as 39 years¹. They face higher risks of mental health issues and co-occurring medical conditions, leading to **elevated rates of suicidality among older neurodivergent adults²**. This underscores the pressing need for improved mental health care access and utilization. Despite recognition of access barriers, research has primarily focused on younger populations, leaving the unique challenges of older neurodivergent adults. Addressing this requires a deeper understanding of their experiences, achievable through qualitative methods like semi-structured interviews. The semi-structured interview is the key tool to explore this phenomenon, and it is critical to have a comprehensive interview guide. This project aims to create an effective interview guide for understanding the experiences of neurodivergent older adults (50 yo+) accessing mental health services.

Methods

Step-by-step approach:



Preliminary Interview Guide

(Script before starting the interview)

Greetings and Introductions:

- Thank the participants for joining and express appreciation for their presence.
- **LEND (Leadership Education in Neurodevelopmental Disabilities) Program Overview**
- Purpose: Provides comprehensive training to future researchers and clinicians.
- Focus: Fostering interdisciplinary care for the neurodivergent community.

Research Context:

- Research interest: Understanding experiences of neurodivergent older individuals accessing mental health care
- Purpose: Developing an interview guide to explore the lived experiences

Recording and Consent:

- Request for permission to record the interview and subsequent discussion.
- Purpose of recording: Tool for self-reflection and critique.
- Consent question: May we have your consent to record our conversation?

Confidentiality Assurance:

- Information discussed will be kept private.
- Identifying information will be removed in transcriptions.

Final Checks:

- Opportunity for questions or concerns before starting.

Commencement of Interview:

- Confirmation of starting recording.
- Expression of gratitude for cooperation and contribution to research.

To begin, we'd like to inquire about your general understanding of mental health.

- Could you please provide insight into your understanding of mental health?
- Can you share your knowledge regarding the existing assistance and support mechanisms available for neurodivergent individuals with disabilities encountering mental health difficulties?
- (Probe) How did you acquire this knowledge?
- (Probe) Are you familiar with resources for addressing mental health challenges? If so, where would you typically seek assistance?

Let's begin discussing your experiences in accessing mental health support.

We can start from your experience with PCP. But before getting started,

- Do you have a primary care provider whom you consistently visit? (If yes, continue) (If not -> how do you get health care service when needed?)
- What is your experience like when discussing your mental health concerns with your primary care provider?
- Has your primary care provider referred you to mental health services?
- If so, what types of mental health services they referred you to?
- Are there any other types of mental health services you have used or tried to get?
- Could you please share your experience with accessing these services afterward?
- Could you please share with us the specific steps you took?
- Is there anything which helped? If so, can you please share what they were?
- Is there anything difficult? If so, what challenges did you encounter during your journey to access mental health support?

- How did you navigate through the process to access mental health support?
- What were your overall impressions of the experience?
- Have you ever found yourself in a situation where you required care for your mental health symptoms, but were unable to receive it? If so, could you elaborate on the factors or obstacles that prevented you from accessing the care you needed?
- What specific areas did you have difficulty? (After they talked about the areas and if not discussed, ask)
 - o Did financial constraints present a significant barrier?
 - o Were transportation challenges a factor?
 - o Did stigma surrounding mental health play a role in your ability to access care?
- Based on your experiences, could you identify any specific challenges or limitations that neurodivergent individuals encounter when attempting to access mental health services?
- Considering the constraints you've mentioned, what kind of support or resources do you believe would have been beneficial for you during that time?
- Alternatively, if you haven't encountered such constraints, could you provide insights into your experience accessing and utilizing mental health services?
- From your perspective, if any, what specific changes or interventions do you believe could enhance the treatment of mental health disorders for individuals currently experiencing them?

(Last question/closure) Thank you for taking the time to tell me about your experience of mental health care access. Is there anything else you would like to share with us regarding the mental health care system itself or access in your community, or anything that we have not touched on?

Final Interview Guide

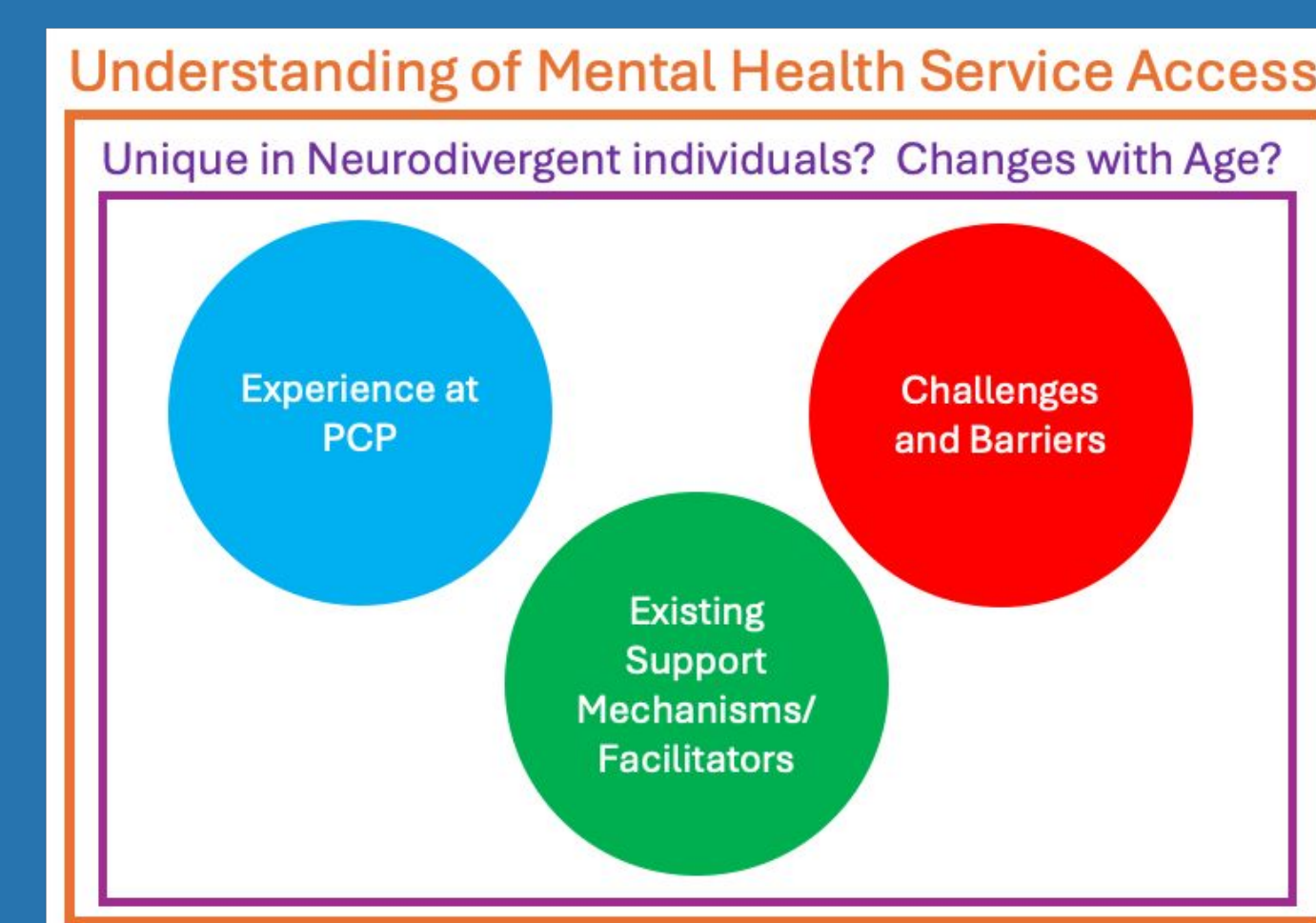
(Script before starting the interview is the same EXCEPT added the icebreaker to get to know the each other. i.e. "What is your hobby?")

Then, move to asking preferences

Before we begin...

- Would you like to keep the camera ON or OFF?
- Would you like to see the interview questions on the screen? Or, would you like us to ask the questions verbally?
- Would you like to answer verbally? Or in writing??

Examples of the interview questions to share with participants



Main question domains:

- Experiences with PCP discussing MH issues
- Access to MH services in general
- MH access experiences, unique to neurodivergent individuals
- Changes of MH access experiences as they age (MH: Mental Health)

Acknowledgement

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References

Check the QR code to see the references



Results

Step 1: The interview guide was inspired by five different papers focusing on different target populations, including African American adults, the Latino adults, adolescents, and older neurotypical adults in general.

Step 2: Identify common themes among these interview guides and tailor questions to fit our target population. Example: Could you identify any specific challenges or limitations that neurodivergent individuals encounter when attempting to access mental health services?

Step 3: Obtain feedback from both supervisors (SV) and peers regarding the interview guide. Feedback included: better flow needed, word clarifications for participants (i.e. neurodivergent). Subsequent adjustments were made accordingly.

Step 4: Conducted a pilot interview with a student who is familiar with neurodivergent community. Spent 50 mins for a pilot interview, 15 minutes for obtaining feedback.

Step 5: We incorporated feedback from the pilot interview (including icebreaker for rapport, and minimizing question repetition). Additional suggestions from SV, her research assistants, and the peers. Feedback emphasized using visual cues for clarity and providing the preferences for interview method. Subsequent adjustments were made accordingly.

Step 6: Conducted the second pilot interview with a neurodivergent individual (45yo, LEND clinic patient, spending 45 minutes on the interview and 15 minutes gathering feedback.

Step 7: We incorporated feedback from the second interview, which included changing one visual aid with many words to the one less words, and adjusting all slides for better visualization during a video meeting.

Discussion

The urgent need to improve the accessibility of the interview for qualitative inquiry among neurodivergent individuals exists because the lack of accessibility may be a potential barrier to participation. Researchers must remain attuned to diverse populations' evolving needs and preferences through continual reflection, adaptation, and refinement (such as providing options, visual cues, etc.). **Methodological Implications:** The adapted interview guide captures a comprehensive range of perspectives and experiences, enriches the depth of data collected, and minimizes the misinterpretation or misunderstanding risk. **Empowerment of Individuals:** The adapted interview guide enables active engagement in the research process, and values and respects the voices of all individuals.

Future research: Studies are needed to assess the validity and reliability of research findings based on the adapted interview guide.

Strength: This project collected information from multiple expertises (the qualitative researchers and RA working with the neurodivergent community, LEND trainees, and the participants).

Limitations: Due to the nature of the project, only a few participants were interviewed.

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