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## Online Supplementary Material

### Section 1: McGill Illness Narrative Interview Guide Modified for Diabetes, Interview Guide for Parent Study, Subjective Experiences of Diabetes Among White and Black Older Adults with Type 2 Diabetes

We have modified the McGill Illness Narrative Interview (Groleau, Young, & Kirkmayer, 2006) to elicit participants' lived experience and understandings of diabetes. This interview guide will continue to evolve as the study proceeds, allowing for the incorporation of early feedback.

#### Introduction

Your name was given to us by the HANDLs study in which you participate. You were selected to participate in this study because you have been diagnosed with Type II diabetes. This interview should last about 1 to 1½ hours but if you want to take a break, we can schedule a second session.

#### Part A. Illness Narrative

*(This section elicits an open-ended narrative of the participant's diabetes history and experience, forming the foundation of the in-depth narrative interview).*

*Establish the participant's term or expression for diabetes. Use this term throughout the interview.*

1. Please tell me the story of your diabetes? How did you find out? What happened? *The interviewer will encourage the narrative to unfold at length with simple prompting, e.g., What happened then? And then?*
2. How and when did you first learn you had diabetes?
3. What were your first thoughts when you learned you had diabetes? What did you think? Did it worry you?
4. What did you do (if anything) after you were told you have diabetes?
5. Did you tell anyone about your diagnosis? Who? What did they say?

#### Part B. Subjective Understanding of Diabetes

1. What does having diabetes mean to you?
2. Why do you think your diabetes started when it did?
3. What do you think causes diabetes? *Probes for causes:*
  - a. What do you think is happening in your body that could explain your diabetes?
  - b. Is there something happening in your family, at work or in your social life that you believe might have led to your being diabetic? If yes, can you tell me more?
  - c. Do you ever think that your diabetes is somehow linked to specific events in your life? If yes, please tell me more?
  - d. Do you believe your diabetes was preventable? Was it inevitable? Probe why.
4. Who do you know (friends, family, neighbors) who has diabetes?
  - a. How is their experience different? How is it the same?
5. What usually happens to people who have diabetes?
6. How has what you've seen, heard, or read influenced your thinking about diabetes?
7. Do you have any physical conditions you think may be related to your diabetes not being under control? *Probe for conditions and how each is related to diabetes*
8. Have you experienced (or are experiencing) any other health problems? *Note the health problems.*

- a. How is your experience with that illness similar from diabetes? How is it different?
  - b. How does your diabetes affect \_\_\_\_ problem? How does \_\_\_\_ problem affect your diabetes?
9. What do you fear most in terms of your diabetes? *Probe why.*
10. How has getting older affected your diabetes? How has it affected how you think about your diabetes?
11. What do you think will happen with your diabetes in the future? Do you think your diabetes will ever go away or be completely better? How do you think that would happen?

### **Part C. Diabetes Management Perceptions and Practices**

1. Has your diabetes changed your life in any way? How?
2. What do you do to take care of your diabetes?
3. What are some things that you can do to improve your diabetes? *Interviewer will probe each of the responses given. Are you able to do these things? Why or why not?*
4. What do you think makes your diabetes worse?
5. Who has been helping you with your diabetes? *Probe for a variety of possibilities and address each answer individually – e.g., medical professionals, lay or religious healers, friends, herbalists, Internet, etc. probe to identify activities done concurrently and consecutively*
  - a. What has been your experience with \_\_\_\_\_? *(Follow their lead by probing about both the positive and negative sides of the experience, including, e.g., accessibility, effectiveness, level of trust and understanding, etc.)*
  - b. What type of follow up occurs between visits?
  - c. What do you talk about during your visits? *Probe for any beliefs, concerns, or problems previously mentioned*
  - d. What have you learned from \_\_\_\_\_ about diabetes?
6. Did you receive any treatment, medicine or recommendations to follow? *List all.*
  - a. How do each of these different treatments or recommendations compare with your own beliefs? *Probe for any incongruence or contradiction between their beliefs and the various treatments or recommendations*
  - b. Have you been able to follow the given recommendations? Why or why not?
7. Have you ever delayed getting care for your diabetes when you thought you needed it or when others have told you to get help? *Probe why*
8. How do your other illnesses affect your ability to get care for your diabetes?
9. Please share about an episode(s) when you have felt your diabetes was out of control. *Probe*
10. Is your diabetes under control now, in your view? What leads you to answer this way?

*If participant has not yet addressed exercise, diet, or medication & monitoring of glucose levels, probe specifically for attitudes, perceptions, and experience with these conventional standards of care.*

11. *Exercise:*
  - a. How much physical activity (of any type) do you get in a day? Describe the activities.
  - b. How has your physical activity changed since you learned that you had diabetes?
  - c. Are you satisfied with your level of physical activity? Why or why not?
12. *Food/Eating:*
  - a. What kinds of things do you eat/drink most often for breakfast? Lunch? Dinner?

- b. Do you cook? If yes, what food do you like to cook? *Probe how often cooks these items*
  - c. How do you get ideas for what to eat/make/prepare?
  - d. Please describe what it means to eat healthy for your diabetes. Describe what it means to not eat healthy for diabetes.
  - e. Are you satisfied with the “healthiness” of what you eat? Why or why not?
13. *Monitoring Glucose/Medications:*
- a. Do you monitor your glucose or blood sugar? *If yes, probe: How often?*
  - b. Do you take insulin or other medication such as pills for your diabetes? Do you take it as often as you are supposed to? Why or why not?
  - c. Are there some medicines you don’t take because of the side effects? What are they?
  - d. Do you take over the counter medicines, vitamins or supplements (e.g. cinnamon) for your diabetes? Have these made a difference? *Probe for how they learned about these ideas.*

#### **Part D. Social Context of Diabetes**

- 1. You told me earlier that you are a [e.g., *mother/father, grandparent, daughter/son, wife/husband*]. How does being a [*mother/father, etc.*] affect what you do for your diabetes each day? *Probe about each relevant social role’s influence on seeking treatment*
- 2. Are you currently working? If so, how does your work affect what you do for your diabetes?
- 3. What are some ways in which your family/friends/neighbors help you (or not) with your diabetes? *Probe: doctor’s visit, other healers, cooking, exercise or staying active, help with glucose testing*
- 4. How do people react to your diabetes? *Probe regarding reactions in different settings: home, work, church, meals, social events*
- 5. Has your spirituality, faith or religious practice/community helped you with your diabetes? How?
- 6. How does where you live affect your ability to take care of your diabetes? *Probe regarding: availability of foods; neighborhood safety; places to exercise; transportation availability*
- 7. How does money/insurance affect how you take care of your diabetes? *Probe for how it affects treatment seeking and at home care, e.g., Can you get your medications, blood glucose testing supplies, diabetic socks and/or shoes? Why or why not?*
- 8. Is it difficult to travel to get to your doctor for diabetes appointments? Why or why not?
- 9. Is there anything else you would like to add?

*As noted in the proposal, Specific Aim 4 (Determine race and gender variations) is addressed through the analysis of participants’ responses.*

## **Section 2: Codes, Themes, and Detailed Explanation of Secondary Analysis**

The analytical process began early in the project; when the original interviews were being conducted, the lead author was beginning to hear a similar pattern among the interviewees. The childhood adversity they shared about in their interviews were being linked by the interviewees, with their current health issues.

Each of the transcripts of interviews conducted by the lead author (n=47) were coded to delve into the topic of childhood adversity – who, how, when was it spoken about. This is what might be called the discovery stage: what kinds of health-related actions (or inactions) were being related or connected with these childhood adversities? What was being implied vs. directly referenced?

Once the discovery coding was completed, the next step was to determine the subsample. Because we did not administer a scale, such as the adverse childhood experiences instrument, we analyzed each interview, noting whether their experiences as children fit an understanding of adversity (from their subjective experience). The codes labeled FACE (family adverse childhood experiences) were defined as “adversity as a child in one’s family”. These categories were both inductively derived and informed by the ACES literature.

FACE\_adversity

FACE\_alcohol/drugs

FACE\_eating issues as kid

FACE\_emotional abuse

FACE\_imprisonment

FACE\_learning or developmental disability

FACE\_negative effects but not egregious

FACE\_neglect/abandonment

FACE\_physical abuse

FACE\_positive aspects

FACE\_sexual abuse

Once the subsample was formed, the codes that grouped into the themes we are presenting in this manuscript, 1) undermining self-worth, 2) overeating and food as comfort, and 3) weight and body size, relate to some of the following codes: FACE\_adversity, FACE\_eating issues, FACE\_emotional abuse, FACE\_neglect/abandonment; body, emotion, mechanism, quote with

linkage, self-management/selfcare. “mechanism” and “quote with linkage” were codes specifying the actions or impact of childhood upon health and well-being in later life.

This manuscript represents only some of the themes/patterns that we identified within the coded material. We specifically targeted those affective practices (health behaviors that have an emotional component) and wrote about themes that were prevalent and repeated themselves and/or were emphasized in a way by the depth and quality of the narrative around these themes.

We include an example of a section of coded interview narrative from a participant who is not quoted in this paper. For this participant, her affective practice for many years was to give of herself to the point of great stress and a disregard for her own health. The codes attached to each section appear in small print in the format ATLAS.ti creates.

**P##: DOC FINAL.doc - 72:65 [It sounds like you’ve got a re..] (490:500) (Super)**

Codes: [FACE\_positive aspects - Family: Family (origin)\_ACE] [LC\_Childhood - Family: Life Course] [LC\_Generativity - Family: Life Course] [LC\_Life History - Family: Life Course] [M\_Pathway - Family: Mechanisms] [M\_Resilience/Compensation - Family: Mechanisms] [Quote with Linkage] [Self-care (lack of or attention to)]  
No memos

Response: My mother, my mother was a strong woman. She raised all her seven kids by herself. She worked two jobs – yes – my father ... my father left my mother and, um, matter of fact he left but he never would divorce her so when he passed away she had to stop and bury him and everything to that nature even though he had done moved on with another woman. And this woman couldn’t do nothing because he hadn’t divorced my mother so she just like stopped in her tracks, I got to put him away, I’m going to do my job and she did that. And, um, my mother has always been the type that will open her door if you needed her and I guess that’s where I got it from because she used to tell me, I used to take care of, my mother had kidney, kidney failure so she went to renal a lot and she used to say when I’m gone you do what you can until you can’t do it no more. She said when you feel as though you’ve had enough and you need to walk away, you walk away, you don’t look back and don’t regret nothing you’ve done.

**P##: DOC FINAL.doc - 72:83 [Response: Uh-huh, she knows it..] (1490:1490) (Super)**

Codes: [Emotion\_Stress - Family: Emotions] [LC\_Generativity - Family: Life Course] [M\_Pathway - Family: Mechanisms] [M\_Resilience/Compensation - Family: Mechanisms] [Quote with Linkage]  
No memos

Response: [My daughter] already told me, she said ma, I don’t know what I’m going to do, she say my diabetes not getting no better and if I have to, um, she said I’m having a hard enough problem sticking my finger checking my blood levels, how am I going to be able to stick insulin. I say well, I do it. I do it first thing in the morning. I do it three times a day. And I do it once at night sometimes. I said so if I can do it, my mother did it before me, you want to be here, you got to do what you got to do to take care of yourself, that’s it.

### **Section 3: Secondary Analysis Complete Coding Scheme:**

Body

Creative Expression -- Art, Hobby, Tradition

Emotions

Emotion\_Anger/Hate

Emotion\_Fear/Trust

Emotion\_Happy/Well-being

Emotion\_Sadness/Hurt

Emotion\_Stress

Emotions\_Guilt/Humility/pride/denial

Emotions\_Love and Affection

Family—Adversity as a child in one's family

FACE\_Adversity

FACE\_alcohol/drugs

FACE\_Eating issues as kid

FACE\_emotional abuse

FACE\_imprisonment

FACE\_Learning or developmental Disability

FACE\_negative effects but not egregious

FACE\_neglect/abandonment

FACE\_physical abuse

FACE\_positive aspects

FACE\_sexual abuse

## Identity

### Life Course

LC\_Childhood

LC\_Cohort, Period Effect or Context

LC\_Death/Dying/End-of-Life

LC\_Generativity

LC\_Life History

LC\_Timing

### Mechanism (M)

M\_Healing/Forgiveness/Understanding

M\_Pathway

M\_Resilience/Compensation

### Method

### Power and Ideology (PI)

PI\_Injustice/lack of agency

PI\_Justice/Agency

PI\_Social Deixis

PI\_Word Choice

### Pivotal Moment

### Quote with Linkage

### Race/Ethnicity/Gender

### Self – Adversity as an Adult



SACE\_domestic violence/emotional abuse

SACE\_drug/alcohol addiction

SACE\_food addiction

SACE\_homelessness

SACE\_imprisoned

SACE\_negative but not egregious

SACE\_sexual addiction

Self-management (lack of or attention to)

Worldview