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Understanding Help Seeking among Black Women with Clinically Significant Posttraumatic Stress Symptoms

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***Abstract*—**Understanding the help seeking decision making process and experiences of health disparity populations with posttraumatic stress disorder (PTSD) is central to development of trauma-informed, culturally centered, and patient focused services. Yet, little is known about the decision making process among adult Black women who are non-treatment seekers as they are, by definition, not engaged in services. Methods: Audiotaped interviews were conducted with 30 African American adult women with clinically significant PTSD symptoms who were engaged in primary care, but not in treatment for PTSD despite symptom burden. A qualitative interview guide was used to elucidate key themes. Independent coding of themes mapped to theory and identification of emergent themes were conducted using qualitative methods. An existing quantitative dataset was analyzed to contextualize responses and provide a descriptive summary of the sample. Results: Emergent themes revealed that active mental avoidance, the intermittent nature of distress, ambivalence, and self-identified resilience as undermining to help seeking decisions. Participants were stuck within the help-seeking phase of 'recognition' of illness and retained a sense of "it is my decision" despite endorsing significant social and environmental negative influencers. Participants distinguished 'help acceptance' from 'help seeking' with greater willingness to *accept* help and importance placed on being of help to others. Conclusions: Elucidation of the decision-making process from the perspective of non-treatment seekers has implications for outreach and treatment within models of integrated and specialty systems care. The salience of responses to trauma symptoms and stagnation in the help seeking recognition phase are findings relevant to integrated care service design and community engagement.

***Keywords*—**Culture, help-seeking, integrated care, PTSD.

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I. Introduction

DISPARITIES in help seeking are frequently cited as explanatory for poorer outcomes among Black women with PTSD [1]. While some data suggest more positive attitudes about seeking help for mental health among Blacks compared to Whites [2], rates of help seeking for PTSD are lower among Black women even when adjusting for symptom severity and other confounders [3]. Evidence-based treatments for PTSD include pharmacology and psychotherapies, yet dropout rates are significantly higher among Blacks with some implication that this is due to more rapid improvement [4] and other studies raising concerns about disparate treatment quality [5]. Identification of the optimal treatment for PTSD requires further research on the mechanisms of therapeutic change, understanding effective "non-specific" treatment elements' role in that change, and identifying service design that maximizes treatment engagement likelihood when indicated [6], [7]. Health disparities that are driven by differences in help seeking must be understood from the perspective of individuals in need of, but not seeking, help.

Qualitative research can provide useful insights to inform efforts to promote help seeking for PTSD, but published studies have poor representation of Black women [8]-[10]. The purpose of this pilot study was to determine how a group of Black women who have clinically significant posttraumatic stress symptoms decide to 'not seek help' for those symptoms and to characterize their help-seeking process. We aimed to identify factors (thoughts, feelings, behaviors, and social/physical environment) that influence help seeking decisions for posttraumatic symptoms, and explore how they navigate help-seeking stages. Using in-depth interview methods, the study engaged (30) participants who were purposively sampled from an existing database. The interviews explored participants' help seeking decision-making process including internal and external levels of response. The interview grid allowed for examination of specified domains as well as facilitate emergence of themes, which were explored in subsequent interviews. We present a brief report of overarching emergent themes relevant to help seeking.

II. Methods

Participants were purposively sampled from the Grady Trauma Project (GTP) Database. The GTP aims to determine

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the relative contribution of genetic and trauma-related risk factors for PTSD in a cross-sectional study of a highly traumatized, low socioeconomic status, minority urban population [11]. Subjects were originally recruited from primary care clinic waiting rooms. Inclusion criteria for the present study were African-American women over age 18, who have clinically significant posttraumatic stress symptoms (as defined by at least one positive response on PSS-SR in each cluster variable or with PTSD diagnosis as determined by CAPS), and speak English as their primary language. Eligible subjects were contacted via telephone, given a brief overview of the study, and invited to schedule consent and interview. Interviews took place between 2013 and 2014. Written informed consent was obtained from participants to participate in the interviews and allow their existing quantitative data to be used in analysis. The Institutional Review Board at Emory University and the Office of Research Administration at Grady Health System approved this study.

Qualitative data were collected through open-ended interviews by the first author who designed the interview grid in consultation with a medical anthropologist informed by the theory of triadic influence and the Andersen model of medical service utilization [12], [13]. The grid was organized via phases of help seeking on the horizontal axis and levels of response on the vertical axis with question probes listed within each paired domain. Interviews began with a brief overview of project goals and recognition of the expertise of lived experience of the participant followed by an invitation to "walk me through your experiences after your trauma to help me understand how you decided not to seek help". From that point, each individual one-hour interview differed in the order and timing of question probes with a bias towards following cues to facilitate spontaneous discussion of the specified domains. Participants were given the opportunity to respond openly, for example, if a respondent was describing their initial experience of posttraumatic symptoms, they were asked 'What did you think was happening to you?' in order to elicit their thoughts associated with the recognition phase of help seeking. Respondents were asked about their feelings and behaviors at each stage of the help seeking process, using probes as needed. In addition, a set of supplemental decision making questions were used to explore this domain in detail if not discussed spontaneously (the interview guide is included in the online supplement). Field notes were taken after each interview to assist with data interpretation.

Interviews were audio recorded, professionally transcribed, and analyzed using Dedoose, a web-application for mixed-methods research. The coding team consisted of two trained research assistants (J.M., M.H.) and the principal investigator (G.W.). Each coder reads transcripts at least twice independently, first to identify salient text reflecting the participants' decision-making process or experience, and second to code based on the interview guide. Excerpts were created and codes generated using a grounded theory approach to identify emergent themes of relevance to help seeking using a constant comparison technique [14]. The coding team met regularly to discuss code applications and to resolve discrepancies. Saturation of data was reached in identification of relevant help seeking themes. Secondary analysis of the existing quantitative dataset for study participants was analyzed using StataCorp (2013. *Stata Statistical Software: Release 13*. College Station, TX: StataCorp LP) to provide descriptive summary of the sample.

III. Results

There were 30 participants ages 21 to 64 (Mean+/- SD age =45+/-12). All were women and self-identified as Black or African American. 43% had highest education of GED or lower and 87% were unmarried. While they all met study criteria for clinically significant PTSD symptoms, 63% met criteria for PTSD diagnosis. Few subjects had sought help at some point for PTSD symptoms (n=3), yet many had sought treatment for depression (n=14).

Although five participants endorsed common barriers such as difficulty accessing mental health, cost of treatment and fear of being judged; overarching help seeking themes related to the recognition of symptoms and the attribution placed on those symptoms. One theme that was common across all interviews was the denial of the need for help despite endorsement of unresolved difficulty. Comments such as "I just put stuff on the back burner, it comes up but I put it back" and "I just tell myself I'm having a moment" seem reasonable but they often followed vivid and dramatic examples of difficulty functioning. No participants identified PTSD as their 'problem' initially and only three currently identified this as the explanatory model for their symptoms. Most identified the trauma itself or their response to the trauma "stuffing it" as the cause of their problems, many attributed PTSD symptoms to "being depressed". This was true despite severity of trauma specific symptoms (re-experiencing, hypervigilance, avoidance of trauma reminders). In introducing the term PTSD "Have you heard of posttraumatic stress disorder or PTSD", three participants engaged in reflection, reported a change in their understanding, "Wow I thought I was just crazy" and indicated an interest in getting help as a result of study participation "I thought that was something only war vets get, I had no idea you could get that from rape". Additional overarching themes include:

Intermittent Nature of Distress. Participants' interpreted trauma related distress remittance as evidence of not needing treatment. "I just need to cry and get it out, then I'm good for a while." This was true even with years of cycles of severe exacerbations. *Active Avoidance-* Avoidance of trauma reminders is part of the diagnostic criteria and has been identified as undermining treatment seeking based on a desire to avoid further distress. Participants described a sense of intentional avoidance and control of this behavior. "I just packed it in" "just pretend it wasn't there". The capacity to avoid and reduce distress was also interpreted as evidence that treatment was not needed or could be further delayed. *View of Strong Self and Optimism.* Some participants were committed to failed self-management based on beliefs grounded in a view of a strong self and optimism. One participant believed that "time" would help things. Despite years of debilitating

symptoms and difficulty in relationships, she held on to the promise that "it would get better". *Symptom Acceptance*. A common view emerged of symptoms "as equal to the trauma" such as "something terrible happened, of course I'm upset". Acceptance of avoidance as consistent with personality or cultural beliefs "I'm a stuffer" "My family is private" was also prevalent. *Help Acceptance*. A surprising finding was that when asked what participants would advise similar women in their situation to do, they all advised them to "get help". Despite their own reluctance, they were very positive towards help seeking. Two women stated that participating in the study was helping them because they believed they were helping "other Black women". This theme of willingness to accept help in the context of helping others was present in every interview.

Participants were asked to share their thoughts on an ideal system or treatment. Help offered in primary care was identified as "easier" and "less stigmatizing" than going to a mental health clinic. Participants were also interested in getting help in their community and in community activism as a way of getting help and "healing from trauma". Illustrative quotes for each overarching theme are listed Table I.

TABLE I
OVERARCHING THEMES AND ILLUSTRATIVE QUOTES

Overarching Theme	Illustrative Quotes
Mental Avoidance *Participant descriptions that reflect an active process of pushing aside symptoms or ignoring the intensity of symptoms*	Quote 1: "And I guess my way of dealing with it or having not to deal with it is try to suppress it until sometimes I look at pictures on TV and it just jogs that memory, hey that looks familiar." Quote 2: "I just felt like it wasn't something- I mean, I don't know. It didn't feel like anything. Like its just okay, I'm having a moment. Get over it." Quote 3: "I didn't do nothing. Like until this day, I still have effects and I don't do nothing. But I'll keep it to myself."
Acceptance of Trauma *Symptoms are understood as being 'equal to the trauma' and not further explored, symptoms are accepted without being questioned*	Quote 1: "I just deal with it, you know, just deal with it and its okay. This is okay, because we know life will go on regardless. I just have to accept it and deal with it" Quote 2: "I believed that when it first happened it would bother me for the rest of my life." Quote 3: Interviewer: "Were there times that you thought about getting help?" Responder: "No, because I-for some reason- felt like it was normal. I don't know why."
Intermittent Nature of Distress *Feeling of not needing treatment*	Quote 1: "Yeah I think I told myself that because that's what I wanted to tell myself. What happened to me wasn't that bad. I got away. It could have been worse" Quote 2: Participant: "I would just get used to everything and get back to normal life" Interviewer: "So when you were feeling upset or on the edge?" Participant: "It's my eyes. This is crazy. I don't know what to say. I just never contributed anything like that to…I just went on about my day" Quote 3: "Because when I think about it, I'm overwhelmed by it. I can't. It's hard for me to function. I can't read and think about what I'm reading. I can't comprehend."
Optimistic thinking *Delaying seeking help in the present for hope that symptoms will improve as time goes by*	Quote 1: Interviewer: "So what did you think would help?" Participant: "I guess just time" Quote 2: "I just kept thinking that it will get better with time" Quote 3: Interviewer: "How much time do you think you would have given yourself?" Participant: "Probably forever. Probably forever. I mean, there are other things that I was told and I still don't deal with it-like my childhood. I mean after those times, well, I don't remember what it was so it must not be important; [I] just go on. So I probably would have done the same."
Religious beliefs *Beliefs about God as a barrier for seeking help*	Quote 1:"I did think about it, but I didn't want to think about it because I figured God would take it away from me." Quote 2: Participant: "Yeah, you couldn't tell anybody because you [aren't] supposed to get depressed" Interviewer: "So the message you got from church was that you don't need help for your depression, that God can help you with it." Participant: "Um-hum. God can help you with it, but they explained that they knew people who were depressed and they end up saying you don't supposed to be depressed, not if you have the holy ghost." Quote 3: "And when you like my mom- I couldn't tell her what was going on. [She'd say] 'my girl, ain't nothing wrong with you. You need to pray and love Jesus and you gonna be alright.' So that's how she was and that's how a lot of people are in church. You have to be selective with who you talk to."
Seeking help for the sake of others *An individual's family members/friends are instrumental in the decision to seek out help*	Quote 1: Interviewer: "So how did you overcome your initial mixed feelings about getting help?" Participant: My Baby Interviewer: "You were thinking about your baby?" Participant: "Uh-hum. Thinking about my [unborn] baby-I was like 'just do it'" Quote 2: Interviewer: "What do you think helped you be so easily persuaded to get professional help?" Participant: "My children. No matter how much advice I got from this person or that person, I had to keep putting in my head 'my babies need this as well.'" Quote 3: Interviewer: "How did you know you needed help?" Participant: "I didn't. A friend of mine suggested that I go to the doctor. They took a rapekit."
Ambivalence *The state of having mixed feelings or contradictory ideas about seeking out help*	Quote 1:"That part of me just be telling me 'Is it [seeking mental health treatment] going to help you? Might not even help you. You don't need that.' But I'm like telling, you know, [myself] today, the positive part [of me] saying 'Yeah, I want to try to get help.' And see, because I have to try to see is it going to help me, I just can't go on the negative side." Quote 2: Interviewer- "It seems like what you're saying is that you're not morally opposed to talking to a therapist, but you have not made the decision that you actually want to do that." Quote 3: "Whatever the treatment was, I think I would have gone through it. I just did not have enough of whatever it took to go in and say look I need help"
Self –blame *Blaming oneself about events that occurred*	Quote 1: "That part of me bothers me. And you know people think I'm strong. My daughters think I'm so strong. I don't know if that was then. Is that still now that I'm so…that I allowed someone to rape me? Not one person, but lots. I bet it had to be over 7 times I've been raped. How did that happen to me? Why didn't I tell someone? I don't understand that

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Overarching Theme	Illustrative Quotes
	part." Quote 2: Interviewer: "So you're saying that the thing that held you back was the strong belief that it was your fault, that you brought it on yourself, there's nothing to be done about it?" Responder: I felt like as a kid when you were where you weren't supposed to be; and what kid don't do [wrong] things sometimes; the mother tells them to do one thing and you do [another]. I felt like [that's] what they would think of me."
Cost as a deterrent *Financial reasons hindered the effort to seek help*	Quote 1: Interviewer: Okay so another time a different doctor sent you to some outpatient mental health clinic, but you didn't have insurance to pay for that." Participant: "Yeah" Quote 2: Interviewer: "And when you're doing that are you looking to try to find something that would help you?" Participant: "Yes" Interviewer: "Okay. What did you find?" Participant: "Not much that I could afford" Quote 3: Interviewer: "What kept you from going?" Participant: "We'd have to pay money."
Fear of being judged *Fear of what others would think of them if they decided to seek help*	Quote 1: "I didn't talk with anyone. I don't like the judgement" Quote 2: Interviewer: "What were you feeling when it was suggested to you to get help?" Participant*:* "That I was crazy; you know only crazy people seek help. I didn't want others to perceive me as crazy" Quote 3: "Whoever I'm talking to, how would they see me? What would be the image they get from me?"
Difficulty trusting others *Uncomfortable telling others about their problems*	Quote 1: "I didn't go to nobody but my mom because I'm the type of person I hate for everybody to know my business. They wouldn't have known what that I was going through a lot of that because I would always hide this or hide that." Quote 2: You know, some people do stuff that- then they put you in this, then they put you in that, then everybody be talking about you, and then, you, I just don't want to live with that."
Going against family to seek help *Hesitation to seek help was largely impacted by suggestions from family members*	Quote 1: Interviewer: "So when you also decided that you needed help when you shared that with your family, they thought you don't really need that." Participant: "[They said] you just talking crazy. I guess they wanted to say I was just frustrated cause I couldn't get answers to the questions that I really need to ask." Quote 2: Interviewer: "You know; I don't believe in that 'what goes on in the house say in the house'. I'm not going to keep quiet about what's going on with me. If I keep saying it long enough, then maybe somebody will pay attention and listen to what I'm saying. You see what I'm saying? Cause I was to the point I didn't want to hurt nobody. I didn't want to hurt myself."
Shame *Feeling of humiliation or distress caused by the consciousness of wrong or foolish behavior*	Quote 1: "I think I'm just too embarrassed. I think that's what it really was. Like I said the feeling of shame and [being] violated- that's what I think really overcame me."
Reserved Personality *Personality type that naturally kept quiet*	Quote 1: Interviewer: "Did you talk to anybody about wanting to get help, like friends or family?" Participant: "No. I'm a 'to myself' person. I just stay to myself most of the time." Quote 2: Interviewer: "So you were kind of a person that kept to yourself?" Participant: "I still do."
Strong, Independent *Mentality of self-reliance*	Quote 1: "I come from a large family and it was not like I didn't have a family. But everybody was so much in their own, take care of yourself, so you don't really lean on them."
Using Faith *Used faith as a way to deal with problem*	Quote 1: "Probably should have been staying and talking to a psychiatrist or something like that, but I didn't. I just talked to my mom and I fell on my knees and I went to church."
Helping Others Prevent Trauma *Helping and advising others to seek mental health treatment*	Quote 1: "Well, I walk around with this thing all the time. And so I feel like if I reach out to others and prevent them even by telling them; it makes me feel better to prevent them from feeling the way I feel." Quote 2: Interviewer: "What would you recommend to someone who is going through what you went through?" Participant: "Find someone to talk to."

IV. Discussion

Although participants were characterized as primarily non-treatment seekers, they exhibited help seeking behavior by engagement in primary care; some women were receiving mental health treatment for other conditions, and demonstrated motivation in prior participation in a research study that involved a mental health screening interview. This willingness distinguishes them from individuals adversely impacted by trauma who are completely disconnected from medical care. This study intended to identify factors relevant to urban, disadvantaged Black women; however, this is a heterogeneous population with cultural nuances that could not be fully explored with this study design. The presence of different types of trauma exposure experienced by participants (combat, sexual, medical), builds on previous study designs limited to singular trauma types. The results shed light on preliminary themes of significance to design of services intended to facilitate help seeking.

Prior qualitative research identified several relevant themes around barriers and facilitators to care confirmed by this study [8]. Yet these women perceive themselves to be in control of their decisions even when negative or dismissive reactions to their trauma disclosure deterred help seeking by their own account.

V. Conclusions

These findings suggest a need for culturally acceptable interventions that are delivered in non-specialty (primary care or community) settings in order to effectively engage this population. They also reflect the need to increase access to effective interventions that address traumatic symptoms and strengthen community based educational efforts, perhaps with a focus on family and friends of those impacted by trauma as opposed to traditional public health approaches that directly target affected populations. Future research should examine interventions that include components that enable a "helping yourself while helping others" experience of treatment. It is

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imperative that clinicians and researchers establish multidimensional community engaged strategies to support women who have experienced trauma and are at-risk for poor help-seeking behaviors. Building on the strengths and resilience of women with symptoms of PTSD may be promising to connecting them to medical care.

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