

## Online Supplement

### Pathways to/through Care for Racial/Ethnic Minorities

There is a growing literature on pathways to care (to the initial evaluation for psychosis) but there is no research on “pathways through care,” or decision-making after the initial hospitalization that leads to solid outpatient treatment engagement (1, 2). Pathways to care (to that first hospital admission) for people of African descent in the United Kingdom are often negative and complex (e.g., coercive, often involving the police and compulsory detention), and the situation is similar in the U.S. (3-8). Potential reasons (e.g., stigma, help-seeking delays, referral delays) for negative pathways to care remain speculative (9, 10).

Moreover, very little is known about why racial/ethnic minorities disengage from care (2) and so refuse a “pathway through care.” A recent systematic review of disengagement studies (3) only found two studies that even mentioned ethnicity (one from Australia (4) and one from the Canada ), and neither offered insight into patients’ reasons for disengaging (2).

We need more knowledge to design interventions that improve engagement for racial/ethnic minority populations (9). This study sought to elicit the factors that affect young people with early psychosis who do not view care as a pathway to a better future, never engage, and “refuse to participate” after their first contact with the system, so that we can spare them the potentially “vicious cycle of negative experiences, coercion, disengagement, relapse and so on”(11). Such an approach may shift the inquiry around continuity of care beyond *predictors* of disengagement (e.g., time to first appointment (12)) and “pathways to care”(1) (e.g., emergency rooms, school counselors) to include the lived experiences, perspectives, and needs of young adults as they seek a “pathway through care”—out of the hospital and back to their homes and lives in recovery.

### Qualitative Studies in First Episode Psychosis Research

Boydell, Stasiulis, et al.’s (5) systematic review of 37 qualitative studies on young people experiencing early psychosis found that few studies were carried out in the US (five of 37), and three out of those five included only the perspectives of caregivers. Very few (six of 37) focused on the critical time during and following the initial hospitalization (13-18). Of the six that did focus on the same critical period we hope to study, three focused on the therapeutic alliance of people who were already engaged in care (14-16), one included only mothers (18), none included people who never attended services (which we include), and none included a focus on decisions about treatment drop-out (19). Also, the numbers of people with early psychosis in these studies were low, with a mean of  $n=8$  participants (e.g.,  $n=5,6,7,15$ ) (13-15, 17). One study included only those engaged in an early intervention program (15). In addition, a new study from Australia

investigated only the thirty people who had engaged (20). Another recent study included engagers and people who disengaged, but only after they had first been linked to specialty early psychosis care (6)

As far as we can tell, there is no literature on the diverse population of young people who never engage in the US (or anywhere). The one qualitative study of “disengagement” focuses on people who tried engaging, dropped-out and then re-engaged, with a mean age of 40 (21). This study includes people who both engage and disengage to offer a variety of perspectives.

Moreover, there is very little qualitative research on racial/ethnic minorities and early psychosis. In a recent systematic review of thirteen studies of the qualitative caregivers’ experiences of help-seeking in early psychosis, the total number of perspectives from racial/ethnic minorities in the U.S. included 33 African American and six Hispanic caregivers (7). In another review of qualitative studies on early psychosis, there were only four studies in the U.S. that included racial/ethnic minorities. Of these, one included four African American and four Hispanic parents (8), one included thirteen African American family members (9), and another included five African American family members and two Hispanic family members (10). Of the three qualitative studies in the U.S. of young adults with early psychosis (that we could find), one included four African American and five Latino young adults (Gioia, 2006) one included 16 African American young adults (6), and one included eight African Americans and four Hispanics (12).

### **Critical Period**

The “clinical staging” approach to a person experiencing a psychotic disorder provides a logical framework in which different stages of the illness require different approaches and interventions (13). Tindall and colleagues’ (14) recent work has suggests that engagement in mental health services for young people with early psychosis is also phased. This study targeted the critical time after a young person is initially hospitalized for a first episode of psychosis when the goal of treatment is to interrupt the episode, engage a young person in care, and return them to work or education (22). We aimed to engage a young person in the study as soon as possible after an initial first episode had occurred and a young person had been hospitalized, but before he or she had “engaged” with outpatient services. Definitions of “engagement” range from a strong therapeutic alliance, to attending a specific number of follow-up appointments, to a person identifying a provider as their own (23-28). While definitions of engagement and disengagement vary widely, a young person is sometimes considered to be “engaged” or “not engaged” after three months of participation in or non-participation in care (3,15). We thus chose the first twelve weeks as the focus of our study on the critical period for engagement decision-making.

## Ethnography and Mental Health Services Research

Previous studies using ethnographic methods have advanced knowledge about “patienthood”(29), stigma (30, 31), continuity of care, and service fragmentation (32-34), help-seeking (35), service refusal (36), meaning-making among early psychosis patients engaged in services (15), the value of peer services (16), and chronicity (37, 38). These studies make plain that young people with early psychosis actively engage in “making sense” of their experiences; at times, by reaching out to others, including professionals and caregivers (15, 16, 20, 39). Like these former studies that advanced knowledge in the field, this study focused on understanding young people in context (at the hospital and at home) as they made decisions about whether or not to continue with care in every day, real-world circumstances.

### Study Timeline

#### RESEARCH PROCESS AND TIMELINE

	Baseline	Week 3	Week 6	Week 8	Week 12
<b>With Young Person</b>	Verify Protected Health Information (Age and Diagnosis)  Informed Consent  Demographic Information Sheet  Interview (1 hour)	Interview (1 hour)  Ethnographic observation (2 hours)	Interview (1 hour)  Ethnographic observation (2 hours)		Interview (1 hour)  Ethnographic Observation (2 hours)
<b>With Key Supporter</b>				Interview (1 hour)	Interview (1 hour)

## **Interview Guides**

### **Person-Centered Interview Protocol for Young Person**

*The following questions, although not necessarily worded in exactly this way, and not necessarily in this exact order (as this is a semi-structured interview), will be asked to individuals alone or in a small group of 1-3 people (as is their preference).*

1. Tell me about your life.
2. Tell me how you came to be in the hospital (*baseline interview only*)? Has your perspective on how you ended up in the hospital changed since our last visit (interview 2,3, and 4)?
3. What are some of the key challenges you are facing today?
4. How would you explain what is going on with you? [Elicit key factors related to school, family, social life, substance use, and work settings.]
5. What resources do you think you need to improve your situation? [Elicit their thoughts on work, education, family life, social life, substance use.]
6. How do you seek out help and how do you refuse help? Why?
7. Would you describe mental health care as a resource or a burden? In what ways? What have been your experiences so far?
8. What resources do they have to improve your situation now?
9. How do you envision your future one year from now? Two years from now? Five years from now? What would best help you achieve your longer-term goals?
10. How important do you think mental health treatment is for your future? Why or why not?
11. What kind of mental health care would you like to receive in an ideal universe? Who would provide it?
12. Who would you say is a “key supporter” for you? Do you think they would talk to us? Why or why not?
13. What do you think being a “key supporter” means?
14. If you could describe an ideal key supporter, what would they be like?

### **Person-Centered Interview Protocol for Key Supporters**

*The following questions, although not necessarily worded in exactly this way, and not necessarily in this exact order (as this is a semi-structured interview), will be asked to individuals alone or in a small group of 1-3 people (as is their preference) during the interviews of key supporters.*

1. Tell me about your life.
2. How do you know [the young person being discussed]?
3. What do you think being a “key supporter” means?
4. Why do you think they consider you their key supporter?
5. What are some of the key challenges [name of young person] is facing?

6. What are some of the main challenges you are facing as [name of young person]'s key supporter?
7. How would you explain what is going on with this young person? [Elicit key factors related to school, family, social life, substance use, and work settings.]
8. What resources do you think they need to improve their situation? [Elicit their thoughts on mental health care at some point—do they think it is a resource or a burden?]
9. What resources do they have to improve their situation now?
10. In an ideal universe, what kinds of mental health “care” would be available to this young person? Who would provide it?
11. How do you envision [young person's] future one year from now? Two years from now? Five years from now? What do you think your role will be?
12. How important do you think mental health treatment is for [young person's] future? Why or why not?

### Coding Techniques

Using Dedoose enabled the team to open-code the text (17). The team developed a codebook, and once no new open codes were emerging from the interviews being collected, or “theoretical sufficiency” (17,18) had been achieved, two independent coders coded each transcript using the codebook, with one applying initial codes and the second one “checking” for correct code usage (19). Coding discrepancies were discussed and resolved by consensus. When needed, the codebook was revised, and data recoded, to ensure consistency.

### Demographics of All Recruited Participants (N=37)

Demographic	N	%
Age	21.8±2.8	
Highest Job Level of Father <sup>o</sup> (n=33)	4±2.0	
Highest Job Level of Mother <sup>o</sup> (n=32)	4.7±1.7	
Gender		
<i>Male</i>	21	55.3
<i>Female</i>	17	44.7
Engaged		
<i>Yes</i>	9	23.7
<i>No</i>	12	31.6

<i>Unknown</i>	17	44.7
Race/Ethnicity		
<i>Asian</i>	4	10.5
<i>Black or African American</i>	15	39.5
<i>Hispanic or Latino</i>	11	28.9
<i>White</i>	8	21
Marital Status		
<i>Single</i>	34	89.5
<i>Married</i>	4	10.5
Parent of young child	7	18.4
Highest Education Level of Young Person		
<i>Some high school</i>	10	26.3
<i>High school graduate</i>	10	26.3
<i>Some college</i>	16	42.1
<i>College Graduate</i>	1	2.6
<i>Graduate degree</i>	1	2.6
Immigration Status		
<i>1st generation</i>	9 (23.7)	23.7
<i>2nd generation</i>	10 (25.6)	25.6
Job Last Month		
<i>Yes</i>	13	34.2
<i>No</i>	22	57.9
<i>Unknown</i>	3	7.9
Highers Education Level of Father (n=34)		
<i>Elementary School</i>	1	2.6
<i>Junior High</i>	3	7.9

<i>High school graduate</i>	14	36.8
<i>Some college</i>	5	13.2
<i>College graduate</i>	3	7.9
<i>Graduate degree</i>	8	21.1
<i>Not answered</i>	4	10.5
Highest Education Level of Mother		
<i>Elementary School</i>	3	7.9
<i>Junior High</i>	2	5.3
<i>Some high school</i>	1	2.6
<i>High school graduate</i>	12	31.6
<i>Some college</i>	6	15.8
<i>College graduate</i>	6	15.8
<i>Graduate degree</i>	6	15.8
<i>Not answered</i>	2	5.3

<sup>9</sup>: Based on the Hollinshead Redlich Index Score, with 1 being a high level executive, 4 being a clerical and sales worker, 7 being an unskilled employee, and 9 being chronically jobless

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