

# Examining the Patient Experience of a Novel African American Transplant Access Program: A Qualitative Study

Joy E. Obayemi MD MS<sup>1</sup>, Ateh Fonteh MD<sup>2</sup>, Harika Reddy MPH<sup>1</sup>, Mary E. Byrnes PhD MUP<sup>3</sup>, Shaina Alexandria PhD<sup>4</sup>, Kiarri Kershaw PhD<sup>4</sup>, Daniela P. Ladner MD MPH FACS<sup>1</sup>, \*Marquita W. Lewis PhD<sup>5</sup>, \*Dineen C. Simpson MD FACS<sup>1</sup>

<sup>1</sup>Division of Transplant, Department of Surgery, Northwestern, <sup>2</sup>Feinberg School of Medicine, <sup>3</sup>Department of Surgery, University of Michigan, <sup>4</sup>Department of Preventative Medicine, Northwestern, <sup>3</sup>Department of Surgery, <sup>5</sup>Department of Medical Social Sciences and Center for Community Health, Northwestern University

## Background

- Black Americans are **~4X** more likely to develop end-stage kidney disease (ESKD) than White Americans<sup>1</sup>.
- However, they **remain underrepresented** on the kidney transplant waiting list due to documented structural and social barriers<sup>2</sup>.
- To address this need, an **African American Transplant Access Program (AATAP)** was created at NM.
- Details about the patient experience of this novel program have yet to be described.

## Research Objectives

Thus, we sought to :

- Understand the experiences and perceptions of AATAP from the **patients' perspective**.



## Methods

- Data Collection:** One-on-one semi-structured interviews with 45 patients currently and previously enrolled in AATAP
- Time Frame:** July 2024 to December 2024
- Recruitment:** Random purposive sampling was used to recruit patients who were in evaluation (A, n=16), waitlisted (B, n=14), and transplanted (C, n=15).
- Qualitative Design:**
  - Theoretic Framework: Phenomenology, Constructivism
- Coding:** Inductive coding was performed using two independent coders (JO,AF).
- Analytic Approach:** Interpretive description using coding, thematic reports, and iterative discussions of emergent themes and thematic schema.

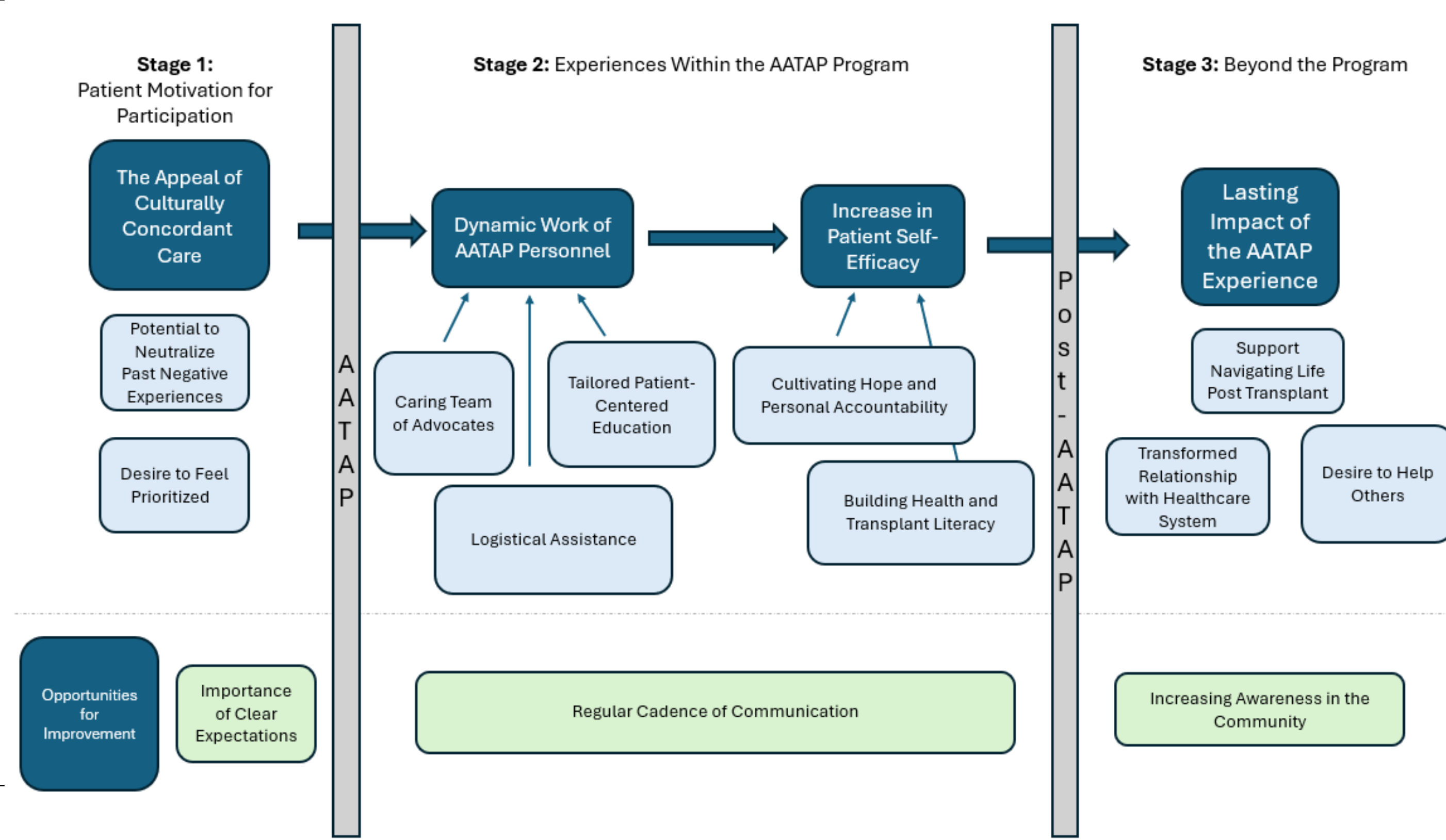
Table 1. Participant Demographics

Demographic	N (%)	Demographic	N (%)
Sex		Employment Status	
Female	20 (44.4%)	Yes	5 (11.1%)
Male	25 (55.6%)	No	40 (88.9%)
Age, mean years (SD)	54.6y (12.8)	Highest Level of Education	
Organ		< High School	4 (8.9%)
Kidney	41 (91.1%)	High School Diploma	8 (17.8%)
Kidney/pancreas	3 (6.7%)	Some College, Technical School, or Associate's Degree	20 (44.4%)
Liver	1 (2.2%)	Bachelor's Degree	11 (24.4%)
Etiology of Kidney Failure		Graduate Degree	2 (4.4%)
Diabetes mellitus	20 (44.4%)	Transplant Phase	
Hypertension	19 (42.2%)	A – In Evaluation	16 (35.6%)
Lupus	3 (6.7%)	B – Waitlisted	14 (31.1%)
ESGS	3 (6.7%)	C- Transplanted	15 (33.3%)
Other	10 (22.2%)		
Time on Dialysis, mean months (SD)	52.2 mo (33.9)		

Table 2. Illustrative Quotes

The Appeal of Culturally Concordant Care	Potential to Neutralize Past Negative Experiences	"I always think that <b>Black people, they don't get treated as fairly as White people</b> ...It's just always been that way with me... And if I'm on a transplant list, I'd get knocked down two or three, and that could mean my life or death. I'm hoping that with AATAP it might be a difference..." (Patient 14B)
	Desire to Feel Prioritized	"[I liked AATAP] because it was for African-Americans...That was actually great because a lot of times African-Americans do not receive the proper medical care that they need. <b>We get brushed off a lot</b> . A lot of our concerns go unnoticed, ignored. So it just felt like, 'Okay, <b>this is for us, made by us</b> .' And again, the whole experience within itself has been awesome." (Patient 11C)
Dynamic Work of AATAP Personnel	Caring Team of Advocates	"I feel held, <b>cared about and protected by this program</b> , in a way that I can't get from my biological family, chosen family, and the few friends that I do have" (Patient 4B)
	Logistical Assistance	"[They helped with] <b>getting all my tests done promptly</b> ...Yeah, there was a couple of things that would kind of hold me back and they were able to get everything situated for me. I don't remember the doctor I was working with before, but they weren't really on top of the ball. So [AATAP] was <b>just a lot more proactive</b> , I should say" (Patient 4C).
	Tailored Patient-Centered Education	"Like I said, [AATAP surgeon] <b>spoke to me on my level</b> . She didn't speak down to me, but she spoke to me on my level..." (Patient 10A)
Increase in Patient Self-Efficacy	Cultivating Hope and Personal Accountability	"Well, they gave me a <b>wake-up call</b> ...clearly I had had to move fast to lose the weight, and I have. If I never came to AATAP...I wouldn't have known I need to lose weight" (Patient 1A).
	Building Health and Transplant Literacy	"Actually, I <b>learned more about kidney transplant</b> [from AATAP], more than the other clinic explained to me when I was trying to get on the transplant. They weren't giving out enough information about it. So when I joined that program, I did get the information that I was looking for..." (Patient 9C)
Lasting Impact of the AATAP Experience	Support Navigating Life Post Transplant	"AATAP has done so much. They have <b>answered so many questions even after transplant</b> ...I know at one point in time I was having issues paying for parking because I'm not working. And I reached out to [AATAP social worker]...So like I say, if anything that you're dealing with or going through mentally, physically, emotionally, financially, <b>AATAP is always there to back you up</b> " (Patient 11C)
	Transformed Relationship with Healthcare System	" <b>I have more of a trust for the doctors through this program</b> ...as opposed to before, I ain't really trust doctors that much like that. And that's probably what brought me to the point that I am now because if I had doctors that I trusted, I probably wouldn't have ended up with the kidney problems and stuff because I would've went to see them. But <b>now I trust them more and try to go to every appointment</b> " (P6B).
	Desire to Help Others	"The ATAAP program is great. I'll always be in it if I can. And even if after I get a kidney, I'll <b>find some kind of way to give back</b> , because I would feel like they have given me... another life... even if I don't get it and I'm able to speak to [others] and let them know, 'Hey, I'm still waiting too. I'm just like you...' <b>So I don't want people to give up hope, because I've been there</b> ...and I'm never going to give up hope" (P12B).
Opportunities for Improvement	Importance of Clear Expectations	"Well, the only thing I would suggest is that maybe they would sit down and <b>have a couple of sessions with you about the things that's going to happen afterwards</b> ...That's the only thing I regret is that I didn't know the after effects of having a kidney with all the medications you have to take..." (P13C).
	Regular Cadence of Communication	"No, I don't think I've talked to any of them since [the transplant]. That would be something that I would recommend though, that <b>they reach out to keep in touch with their patients after the fact</b> " (P4C)
	Increasing Awareness in the Community	"[AATAP needs] maybe a <b>broader way to get it out to more patients on the program</b> because... Like I said, I've seen a clip of it on the news, which got me interested in trying to seek out the program, but if I had not seen that on the news, I don't know that I would have known about it because, yeah, <b>the social worker at my clinic had never mentioned it</b> ..." (P13A).

Figure 1: Thematic framework



- Patients described **5 inter-connected themes**: 1) The appeal of culturally concordant care, 2) The dynamic work of AATAP personnel, 3) Increase in patient self-efficacy, 4) Lasting impact of the AATAP experience, and 5) Opportunities for improvement.

## Conclusions

- A transplant access program that is tailored to the needs of Black patients appears to have been **well-received by patients, increase their self-efficacy** while pursuing transplantation, and result in **lasting positive change** for patients and their communities.

## Acknowledgements

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## References

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