

# Count Me Out: Investigating why dialysis patients are never placed on, or elect removal from, kidney transplant waitlists



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## Introduction

- **Chronic kidney disease (CKD)** affects approximately 20 million people in the U.S., which is 10% of the adult population<sup>1</sup>
- CKD patients who develop **end stage renal disease (ESRD)** “stage 5 CKD” need dialysis or a kidney transplant to survive
- ESRD is characterized by **striking racial disparities**. African Americans are 3.5 times more likely to develop ESRD than Whites; Hispanics are 1.5 more likely to develop ESRD than non-Hispanics<sup>1</sup>. Racial disparities are driven by social and biological factors, including higher prevalence of hypertension and diabetes in minority populations, socioeconomic disparities, and genetic factors<sup>2</sup>
- There are **disparities to progression to transplantation** which include race/ethnicity, insurance status, and income; these are only partially explained by factors such as insurance status and income, notwithstanding Medicare entitlement for these patients<sup>3</sup>

## Purpose

- Investigate **patients’ perceptions** of barriers or other factors which may drive the decision to not be on a transplant list, or be removed from it
- There is a tremendous opportunity to **improve ESRD patients’ understanding of treatment options**, specifically for vulnerable patients concerning kidney transplant
- Research questions:
  - **RQ1:** What are the perceived barriers to getting on a kidney transplant waitlist?
  - **RQ2:** What are the perceived barriers to staying on a kidney transplant waitlist?

## Methods

- Conducted in-depth, semi-structured interviews with (n=25) individuals living in Detroit who are **on dialysis** and are **not currently on a kidney transplant waitlist**.
- Given the racial and socioeconomic disparities associated with ESRD, we selected **Detroit due to its high proportion of African Americans (76%) and percentage of families living below the poverty line (29%)**<sup>4</sup>
- Probed **their experiences as patients and their perceptions of potential barriers**

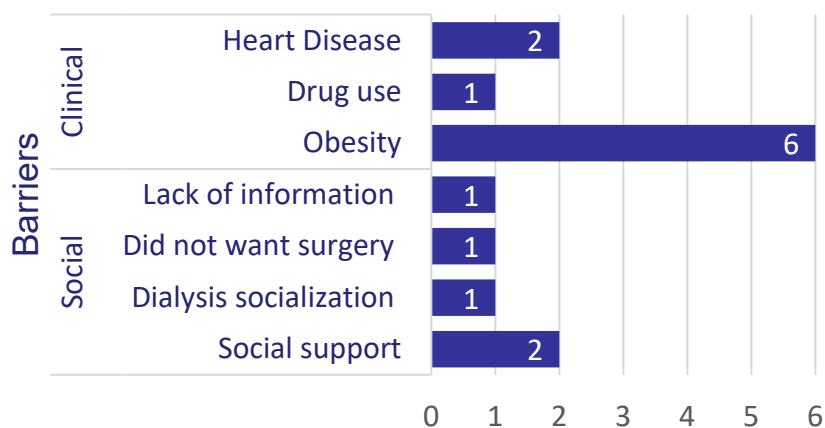
## Results - Participants

Patient	Gender	Age	Race	Start Dialysis	Ever on Waitlist
Pt01	M	46	AA	6 years ago (roughly)	Yes
Pt02	F	60	AA	2004	No
Pt03	M	57	AA	2011	Yes
Pt04	F	34	AA	2012	No
Pt05	F	55	AA	2006	No
Pt06	F	35	AA	1985	Yes
Pt07	F	69	AA	2004 & 2015	Yes
Pt07	F	54	AA	2004	Yes
Pt09	M	56	AA	2004 & 2011	Yes
Pt10	F	72	AA	2005	Yes
Pt11	M	36	AA	2010	Yes
Pt12	F	70	AA	2013	Yes
Pt13	M	57	AA	1994	Yes
Pt14	M	49	Caucasian	2014	Yes
Pt15	M	41	AA	2008	Yes
Pt16	F	55	AA	2013	Yes
Pt17	F	63	AA	2008	No
Pt18	F	73	AA	2010	Yes
Pt19	M	48	AA	2010	Yes
Pt20	M	43	AA	2009	No
Pt21	M	67	AA	2011	Yes
Pt22	F	33	AA	2013	Yes
Pt23	F	58	AA	2011	No
Pt24	F	63	AA	2010	No
Pt25	F	55	AA	2006	Yes

## Findings

- None of the participants are currently on a waitlist, but **most expressed interest** in them
- About half of the participants **did not get on a waitlist upon starting dialysis** because they were experiencing so much **anxiety and fear** about ESRD/dialysis that they either dismissed or don't recall social workers mentioning the waitlist

## Barriers to Transplant Waitlists



Number of Participants (n=14)\*

\*11 did not provide a single, clear reason

- Barriers to getting on a waitlist are fairly **well understood** by participants and are classified according to clinical and social.
  - **Clinical** barriers range from needing to lose weight, to other health conditions (e.g. Congestive Heart Failure)
  - **Social** barriers include not wanting “any more surgeries” to low social support, a criteria for getting on and remaining on waitlists
- Participants **believe that they have a good chance** of getting a kidney once they reach their weight or clinical goals and they generally have a good understanding of the goals they need to reach

## Conclusion

- Participants who were getting screened through their Primary Care Physicians (PCPs) had **knowledge and interest** about transplant waitlists – participants who found out that they would need to start dialysis during an admission to the emergency department were not being screened by a PCP.
- There is a very strong **‘community’ among the dialysis patients** which has provided them considerable information about the waitlists and moral support to help with the considerable burden of being on dialysis
- Most are satisfied with the care they are getting but information about waitlists, diet, and proper self-care has been gleaned over **after several years largely through peers during dialysis or waiting to start a “run”**
- Social workers should consider **when information about waitlists is discussed**, as the emotional burden of starting dialysis may not be the optimal time to discuss treatment options

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## References

1. Center for Disease Control *National Chronic Kidney Disease Fact Sheet: General Information and National Estimates on Chronic Kidney Disease in the United States, 2014*. 2014.
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