

Patient perspective of hyperkalemia management: a focus group study

Sheena Patel, MS, RDN, Ryan Woolley, MSPH, RDN, Melanie Paris, MA, MPH, Michael Spigler, MCHES®

Introduction

- Hyperkalemia is a condition in which potassium levels in the blood are too high, often associated with chronic kidney disease (CKD).
- People with CKD are at an increased risk for hyperkalemia, which can be a life-threatening complication.
- Proper potassium management is crucial; however, application of potassium management varies in clinical practice:
 - Inconsistencies exist across different guidelines for blood potassium levels (high vs low) as outlined in the [Kidney Disease Improving Global Outcomes \(KDIGO\) guidelines](#).
 - Variability in professional use of guidelines in practice.
 - Newer evidence on effectiveness of medical interventions, like medication use, has not made its way into current guidelines.
- Considering these inconsistencies and changing professional guidelines, American Kidney Fund (AKF) sought to understand the perspective of individuals with CKD to identify gaps in hyperkalemia management knowledge.

Methods

- 1 AKF recruited individuals through Facebook, email newsletter and word of mouth. People interested filled out an online screener form to sign up. The online screener captured their demographic information including CKD and hyperkalemia diagnosis, age, race/ethnicity and gender. Eight participants were recruited for the focus groups.
- 2 AKF conducted 2 virtual focus groups of individuals with CKD, one group with a history of hyperkalemia and the other with no history of hyperkalemia.
- 3 Focus groups were recorded, transcribed and transcripts were thematically analyzed.
- 4 From the focus group analysis, 4 main themes were identified.

Results

AKF identified 4 themes through focus group interviews:

1. Those diagnosed with hyperkalemia demonstrated a high understanding of the condition, emphasizing dietary management, while those without hyperkalemia exhibited moderate comprehension but struggled to articulate the specifics.
2. The two common questions that patients have are centered around the cause of hyperkalemia and appropriate food choices and dietary recommendations.
3. Individuals with hyperkalemia mainly manage the condition through dietary changes—eating foods low in potassium and avoiding foods high in potassium.
4. Patients expressed a preference for accessing educational materials online or through their healthcare providers in print or electronic format.

Figure 1. Format for material on managing high potassium

Format	People with hyperkalemia	People without hyperkalemia
Print material	3 of 4 ●●●○	4 of 4 ●●●●
Electronic material	3 of 4 ●●●○	4 of 4 ●●●●
Emailed newsletter	2 of 4 ●●○○	4 of 4 ●●●●
Video	2 of 4 ●●○○	3 of 4 ●●●○
Graphic or visual	0 of 4 ○○○○	1 of 4 ●○○○
Audio	4 of 4 ●●●●	2 of 4 ●●○○

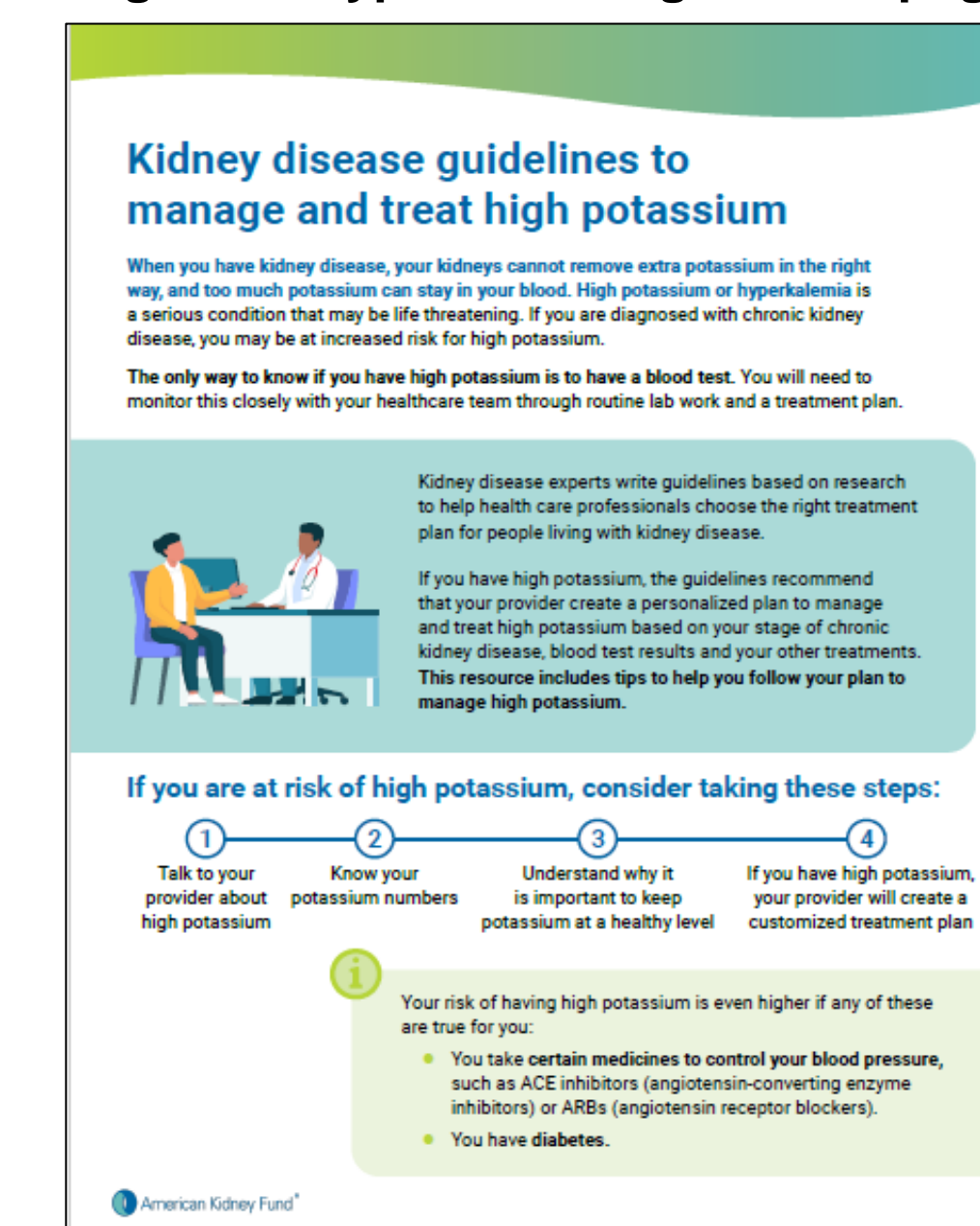
Figure 2: Topics to include in hyperkalemia guidelines

Topics	People with hyperkalemia	People without hyperkalemia
What is high potassium	●	●
Causes of high potassium and its connection to kidney disease	●	●
Is it hereditary	●	
Why it's important to keep potassium at a healthy level		●
Symptoms of high potassium		●
How to lower potassium level and keep it at a healthy level	●	●
List of foods that are high in potassium		●
Alternatives to high potassium foods	●	
List of foods that are low in potassium		●
What to do in emergency from high potassium		●

Figure 3: Supporting quotes from focus group participants

People with hyperkalemia	People without hyperkalemia
<p>Their thoughts focused on tips to manage hyperkalemia:</p> <ul style="list-style-type: none"> • “Just watch what you eat. Read those labels and keep your doctor appointments. Because that follow up and follow through is what’s going to keep you moving forward and staying healthy. Don’t give up.” • “Talk with your family and let them know this is what we need to do [regarding food choices] and I need you all to be on board.” • “Don’t be afraid to ask questions and be honest with your doctors. Honesty will get you a long way.” • “Talk to the primary medicine and the dietician and everything. It’s all right.” 	<p>Their thoughts focused on using simple language, so the material is easy to understand:</p> <ul style="list-style-type: none"> • “I think it should be written in a language that’s layman’s terms because that can be confusing. Lower income individuals tend not to read as well or be bilingual. Need to give them information on their level.” • “I am a stickler when looking at data, I would like to have it in plain language and a clear explanation of ranges and when you should be concerned. Have the meanings of low and high.”

Figure 4: Hyperkalemia guideline page 1



Conclusion

- Using focus group findings, AKF created a 4-page patient friendly hyperkalemia guide that explains both the latest guidelines while also addressing lifestyle management options that patients were looking for.
- Future research should assess the utilization of the patient-facing material and its effect on patient outcomes.

References

1. Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. *Kidney inter., Suppl.* 2013; 3: 1–150.

Acknowledgements




American Kidney Fund thanks AstraZeneca for its generous support of our public education programs and campaigns.



Learn More



[KidneyFund.org/Potassium](https://www.kidneyfund.org/Potassium)

-  [Facebook.com/AmericanKidneyFund/](https://www.facebook.com/AmericanKidneyFund/)
-  [Instagram.com/AmericanKidneyFund/](https://www.instagram.com/AmericanKidneyFund/)
-  [Twitter.com/KidneyFund](https://www.twitter.com/KidneyFund)