

Barriers to Treatment Adherence for Dialysis Patients



The American Kidney Fund (AKF) is the nation's leading nonprofit organization working on behalf of the 30 million Americans with kidney disease. AKF helps people fight kidney disease and live healthier lives through kidney disease prevention services and top-rated health educational resources, clinical research, and critically needed charitable assistance that helps 1 in 5 U.S. dialysis patients to access lifesaving medical care, including dialysis and transplantation. AKF is a top-rated charity that spends 97 cents of every donated dollar on patients and programs. Our direct connection with dialysis patients is unparalleled among kidney organizations and positions us uniquely to gather information that can be used to advance understanding of treatment issues related to the disease and the challenges patients are facing.

KidneyFund.org



FOREWORD

Anyone who is a dialysis patient, loves a dialysis patient or treats a dialysis patient knows that living with kidney failure is enormously challenging. To have the best possible outcomes, it's essential for patients to be adherent to a treatment regimen that is complex and demanding.

Why is it so hard for patients to follow their treatment regimen? Are there barriers that make it more difficult for some patients? Are there interventions that could help patients be more adherent? These were some of the questions we set out to answer with the American Kidney Fund (AKF) Adherence Survey. We wanted to hear—from dialysis patients—where they struggled most with adherence and why. And we wanted to hear from renal professionals what they thought about the reasons patients don't always follow their treatment plans.

Because AKF has direct connections to dialysis patients and renal professionals through our patient assistance programs, we were able to survey more than 1,000 patients and nearly 400 professionals—a large sample by any standard.

This survey report captures the key findings of our survey, some of which may confirm what you already knew and others that may surprise you. More than anything, we want this survey to foster a deeper understanding of the challenges patients face so that all of us—patients, family members, caregivers, health care professionals, and advocacy and support organizations—may more effectively support patients in achieving their best possible health.



LaVarne A. Burton
President and Chief Executive Officer
American Kidney Fund
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AMERICAN KIDNEY FUND ADHERENCE SURVEY

Treatment of end-stage renal disease (ESRD, or kidney failure) is demanding, multifaceted and complex, requiring strict patient adherence to treatment protocols to achieve favorable health outcomes and a satisfactory quality of life. Nonadherence to treatment among dialysis patients is widely recognized in the renal community as an important contributor to suboptimal treatment and poorer health outcomes. Dialysis patients face intricate challenges in consistently maintaining the prescribed routine of limiting fluid intake, maintaining dietary requirements, attending regular hemodialysis sessions and taking multiple medications. Nonadherence can lead to hospitalizations, adverse health effects or even death.

The American Kidney Fund (AKF) conducted surveys of dialysis patients and renal professionals to identify the most significant challenges related to adherence to dialysis treatment, with the goal of better understanding the common barriers that make it difficult for patients to stick to their treatment regimens. Because AKF has a direct connection to 1 in 5 U.S. dialysis patients (through its financial assistance grants), the organization is uniquely positioned to advance understanding of treatment issues related to the disease and the challenges patients are facing.

The American Kidney Fund Adherence Survey was developed based on in-depth interviews with 12 dialysis patients and eight renal professionals. The interviews identified five common non-adherent behaviors:



SKIPPING A DIALYSIS SESSION OR ENDING IT EARLY



NOT FOLLOWING RECOMMENDED DOSES OF MEDICATION



EATING OR DRINKING MORE FLUIDS THAN RECOMMENDED



NOT FOLLOWING A PRESCRIBED DIET LIMITING PHOSPHORUS, POTASSIUM AND SODIUM



BEING INACTIVE OR SEDENTARY.

A 33-question survey was developed and mailed to 3,001 randomly selected patients from AKF's Grants Management System, a database of more than 100,000 primarily low-income dialysis patients in all 50 states who qualify for the organization's financial grants. Nearly 1,200 patients responded—a response rate of nearly 40%. An electronic survey was emailed to 14,216 renal professionals; 374 responded, for a response rate of 2.6%.

The results provide insight into factors that contribute to nonadherence, as well interventions that may demonstrate potential for improving patient adherence to treatment requirements.

KEY FINDINGS

The AKF survey results showed patterns in lack of adherence related to age, mental health status, and patient–health care provider communication. Patients aged 18 to 39 reported lower adherence to nearly all treatment recommendations than patients in any other age group. These patients also indicated feeling depressed nearly twice as often as older patients—and depression emerged as a leading contributing factor to nonadherence across all age groups: More than 40% reported that sadness, nervousness or fear had prevented them from complying with required treatments in the previous month.

The survey also found:

- Over 30% of patients reported leaving dialysis sessions early, while 18% said they skipped sessions altogether. Feeling sick and having conflicting medical appointments are the top reasons cited by patients for skipping or leaving a dialysis session early.
- More than half (58%) of patients reported nonadherence to diet recommendations. The

most commonly cited reason was the desire to take a break from the strict diet (45%). A smaller but still significant number of patients reported not adhering to dietary recommendations if they were difficult to follow when dining out (39%).

- Forgetfulness was the top reason for medication nonadherence (69%). The number of pills a patient has to take did not emerge as a factor in patients’ adherence to their pill regimens.
- 75% of patients who reported missing one pill or dose of medication also reported skipping more than one in the past week.
- Ineffective communication between patients and health care providers is a key factor contributing to nonadherence. Providers said having insufficient time and resources to communicate health information contributes to patient nonadherence.
- Support from non-medical caregivers, such as family members, can improve adherence to diet and exercise regimens.

PERCENTAGE OF PATIENTS ADMITTING TO NONADHERENCE



31%

End a dialysis session early



18%

Cancel/skip a dialysis session



23%

Do not follow recommended doses of medication



51%

Eat or drink more fluids than suggested



58%

Eat or drink more sodium, phosphorus, potassium or protein than suggested



42%

Are inactive or sedentary

“When they first start they go through a lot of emotions and loss, especially in the first 90 days. They become depressed and they don’t see the point. As social workers we try to motivate them, encourage them by making things more fun.”

–renal professional

“I have not been diagnosed but I’ve self-diagnosed with anxiety and depression. I have been trying to get a transplant and I just got turned down by a hospital.”

–dialysis patient

AGE AND ADHERENCE

Compared to all other groups surveyed, the least adherent patients were those who were young and unemployed. Patients between the ages of 18 and 39, the youngest age group surveyed, were least adherent across almost all treatment areas:

- 50% of patients between the ages of 18 and 39 reported leaving dialysis sessions early, compared to 24% of patients aged 60 and over.
- Patients aged 18 to 39 are twice as likely to skip dialysis sessions (30%) as patients aged 60 and over (15%).
- Patients in the 18 to 39 age group reported medication nonadherence at a higher rate (38%) than patients 60 or over (21%).
- Patients aged 18 to 39 reported the highest rate of diet nonadherence (71%) compared to patients aged 60 and over (51%).

DEPRESSION AND ADHERENCE

According to the National Institute of Mental Health, depression is a common but serious mood disorder which causes symptoms that can severely impact one’s feelings, thoughts, sleep, appetite, employment and participation in common daily activities. When these symptoms are present for at least two weeks, a diagnosis of depression is warranted.

Forty-two percent (42%) of patients indicated that depression, nervousness or fear had kept them from activities they wanted or needed to perform in the last month. Patients aged 18-39 reported higher rates of debilitating feelings of sadness (36%) than patients aged 40-49 (18%), 50-59 (20%) and 60+ (18%).

Of patients who reported experiencing depression twice a month or more, 28% skipped a dialysis session, compared to 14% of patients who never felt depressed. Patients who felt depressed at least once a month skipped medication at higher rates (30%) than patients who never felt depressed (18%).

Depression also contributes to nonadherence to recommended fluid intake. Patients who felt depressed at least once a month strayed from fluid intake recommendations at higher rates (60%) than patients who never felt depressed (45%). Furthermore, patients who felt depressed twice a month or more reported discomfort talking to their health care teams at a higher rate (18%) than those who never felt depressed (9%). Finally, 49% of patients

who reported having depressed feelings twice or more in a month said they never exercise, compared to 39% of patients who reported never feeling depressed.

SKIPPING A DIALYSIS SESSION OR ENDING IT EARLY

Life-sustaining dialysis treatment for ESRD requires multiple weekly treatments on a set schedule. Yet over 30% of patients reported leaving dialysis sessions early, and 18% reported skipping sessions altogether in the past month. Though feeling sick was the primary reason patients cited for skipping (59%) or leaving a dialysis session early (41%), nearly a quarter (23%) of patients who left dialysis sessions early and 18% who canceled dialysis sessions did so because of a conflicting medical appointment. Lower percentages of patients cited other factors—including boredom/restlessness, feeling overwhelmed, not wanting to sit for such a long time, and transportation issues—for skipping a dialysis session or leaving early. But these factors were cited more often by patients who ended their treatment early two or more times in the previous month.

Patients receiving dialysis treatment for fewer than five years were more likely (35%) to end a dialysis session early than those who have been on dialysis for five years or longer (26%).

“Dialysis is double-edged sword. You will never make a recovery but you have to keep doing it to stay alive.”

—dialysis patient



While renal professionals recognized that sickness and other patient-centered factors are the primary reasons patients skip or leave dialysis sessions early, they also cited their own challenges as likely contributors to patient nonadherence. For example, 72% of professionals said patients leave dialysis sessions early because staff are unsuccessful in motivating them to stay, while 50% said that patients leave dialysis early because professionals do not have time to try to get them to stay and 49% said they had difficulty conveying the health consequences of leaving a session early. Similar proportions of professionals cited identical reasons for patients skipping dialysis appointments entirely.

Though federal law requires health facilities to provide interpreters to patients who have limited English capabilities, one-third (33%) of professionals cited language barriers as a reason patients missed dialysis appointments, and 24% reported that language barriers prevented patients from asking questions about their treatment.

“They are on 20+ meds a day. It is really hard for them to be 100% on top...It is overwhelming trying to keep track of it.”

—renal professional



NOT FOLLOWING RECOMMENDED DOSES OF MEDICATION

Dialysis patients frequently have comorbidities such as diabetes and high blood pressure, and are often prescribed medications to treat those conditions in addition to the medications they take for ESRD. Overall, 23% of patients said they skipped or missed at least one pill once or more a week, citing forgetfulness as the most common reason (69%). Among patients who missed taking phosphorus binders (which must be taken with a meal), 34% said they left their pills at home when dining out.

Other reasons patients cited for medication nonadherence included cost of medication (16%), difficulty in keeping track of medications (14%), negative side effects (10%), and reluctance to take their medications in front of other people (5%).

Among the 23% of patients who reported skipping or missing at least one pill or dose of medicine within the past week, 75% said they had skipped or missed more than one pill or dose.

According to survey results, the number of pills a patient had to take did not emerge as a factor in patients' reported adherence to their pill regimens, though the in-depth interviews with patients and professionals (conducted prior to the development of the survey) indicated it might.

Renal professionals likewise identified forgetfulness as the primary reason for medication nonadherence (94%), though the majority of professionals also cited cost (88%) and complexity (81%) as factors.

PATIENT REASONS FOR MISSING/SKIPPING MEDICATION DOSES



Forget to take medicine



Leave phosphorus binders at home when out



Medicine too expensive



Medicine doesn't make me feel better



Hard to keep track of medicines



Medicine makes me feel worse



Don't like to take medicine around others



It's hard/hurts to swallow pills



Not sure how/when to take medicine



Some other reason



None of the above



Don't know

As with dialysis treatment adherence, many renal professionals said factors within their control may contribute to patients' medication nonadherence: 48% said staff had difficulty explaining the importance of medication adherence and following medication regimens to patients. More than 40% cited lack of time, language barriers, and lack of resources or knowledge as contributing to medication nonadherence.



NOT FOLLOWING A PRESCRIBED DIET LIMITING PHOSPHORUS, POTASSIUM AND SODIUM

Because dialysis only replaces some of the functions of the kidneys, patients must follow a strict diet as part of their treatment plan—a diet that is typically high in protein and low in sodium, potassium and phosphorus. Nonadherence to the restrictive ESRD diet is common: More than half (58%) of patients reported nonadherence to diet recommendations within the past week.

The most commonly cited reason for diet nonadherence was the desire to take a break from the strict diet (45%), though 39% of patients said they are less likely to adhere to their dietary regimens if the diet is hard to follow when dining out.

Nearly a quarter of patients (24%) said they were not adherent to their diet because they did not like the recommended foods, and 18% cited food cost as a barrier to adherence. Additional factors contributing to nonadherence—not liking to cook (11%), family and friends not liking the recommended foods (10%), and not having time to cook (7%)—could potentially be overcome by providing patients with simple, affordable and flavorful recipes that reflect cultural preferences, and teaching cooking techniques that improve food palatability.

While patients who reported deviating from their dietary recommendations once a week said that consultation with a dietitian did not improve their diet adherence, patients who reported straying

from their recommended diets more frequently said that a dietitian consult improved their adherence.

Renal professionals' perception of the reasons for diet nonadherence mostly aligned with what patients reported, though professionals ranked eating out as the leading barrier (93%), followed by dislike for recommended foods (91%) and wanting to take a break from the diet (90%). A significant percentage of professionals cited factors suggesting their patients do not fully understand or accept the importance of the diet to their health: 82% said their patients think they can rely just on dialysis and do not understand the consequences of diet nonadherence; 76% said their patients have trouble understanding food nutrition labels and 70% said their patients are unsure about what to eat.

Renal professionals acknowledge they have a role in patients' lack of adherence to dietary requirements. They cited language differences (44%), lack of time to adequately counsel patients on diet (43%), and scarcity of educational resources to educate patients about diet (33%) as barriers to adherence among their patients.

Professionals reported that, specifically, patients tend to have more difficulty adhering to phosphorus (24%) and sodium intake (22%) guidelines than those for potassium (8%) and protein (7%).

"Any person on a diet wants to see the results now. And if you don't see the results in a couple of days or weeks, you give up."

-dialysis patient

PATIENT REASONS FOR STRAYING FROM THEIR DIETS



Felt like taking a break



Too hard to follow diet when eating out



I don't like the recommended foods



Recommended foods are too expensive



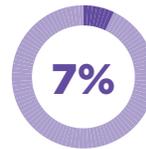
Don't like to cook



Family/friends don't like recommended foods



Not sure what I should eat



I don't have time to cook



Some other reason



Don't know



None of the above



EATING OR DRINKING MORE FLUIDS THAN RECOMMENDED

Though dialysis effectively removes excess fluid from the body, patients must still limit their intake of liquids to avoid a buildup of fluids, which may lead to excessive swelling, high blood pressure and/or congestive heart failure.

More than half (51%) of patients reported nonadherence to their recommended fluid restrictions. The primary reasons were thirst (58%) and dry mouth (48%)—factors that may be linked to comorbidities such as diabetes and side effects of certain medications. Just over one third of patients surveyed (34%) reported not realizing that some foods, such as gelatin, are also fluids, despite their altered appearance or consistency.

Professionals also recognized that thirst is a primary driver of nonadherence (95%), but they cited additional reasons they believe patients exceed the recommended fluid intake. These include patients erroneously believing that dialysis alone is sufficient to address excess fluid (92%), and patients not fully grasping the health consequences of excess fluids (83%). They ascribe some

“They don’t see the point of controlling their diet if they don’t see any improvement. It is too much hard work. They think ‘I don’t feel any different so why do it. Why does it matter?’ They cannot associate these small diet things until a major thing happens further down the line.”

—renal professional

PATIENT REASONS FOR TAKING IN TOO MUCH FLUID



I am thirsty



My mouth feels dry



Too hard to keep track of fluid intake



Forget that some foods count as fluids



I like the taste of certain drinks so I drink more



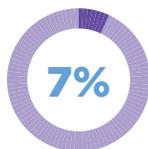
Felt like taking a break



Forget how much fluids to eat/drink every day



Not sure the amount of fluids should drink



Some other reason



Don't know

of their own challenges in educating patients as factors in nonadherence: 42% cited language barriers, while time constraints in educating patients were cited for both explaining how to limit fluids (41%) and explaining its importance (39%). Lack of educational resources was noted by 35%.



BEING INACTIVE OR SEDENTARY

Simple physical activity, such as walking, can have vital health benefits for individuals with kidney disease, yet the motivation among many dialysis patients to adopt this activity appears limited. Among patients surveyed, 58% reported they are adherent to activity and exercise recommendations. Of the 42% who were not adherent to physical activity recommendations, 61% reported they felt too tired, 24% did not feel like exercising, and 17% felt too sick to exercise. Additionally, among those who self-identified as depressed, 60% indicated they never exercise.

Furthermore, retired patients reported less adherence to exercise recommendations than

employed and unemployed patients. 56% of all patients reported engaging in light activity, such as walking, hiking, or cleaning, at least once a week, but retired patients reported lower rates (52%) than employed (68%) and unemployed (64%) patients. The vast majority of patients reported never engaging in moderate activity such as swimming or jogging (76%), or vigorous activity such as team sports or weight lifting (85%).

Perceptions held by renal professionals regarding low rates of patient physical activity aligned with patient reports: 92% said patients often think they are too sick to exercise, and 92% said patients are too tired to exercise. 86% of professionals cited depression as a factor preventing patients from following exercise recommendations. They also noted that staff do not emphasize exercise as a component of care (71%), focusing instead on medication, diet, fluid and dialysis adherence (79%). As with other nonadherent behavior, professionals cited lack of time and resources and language barriers as factors contributing to patient nonadherence.

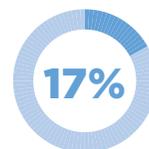
PATIENT REASONS FOR INACTIVITY



Too tired to exercise



Didn't feel like exercising



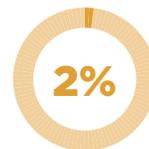
Too sick to exercise



Feeling down or blue



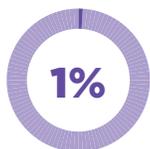
Too busy



Doctor ordered to not exercise



Some other reason



None of the above



Don't know

ADDITIONAL INSIGHTS

Patients' perceived value of a treatment also affects adherence. Patients reported they are more likely to adhere to treatment recommendations that they believe have a positive impact on their health. For example, they were more likely to attend their dialysis appointments than to exercise: 11% of patients reported not understanding the impact of exercise on their condition, nor did they believe that exercise could improve their outcomes. Among patients who were nonadherent to their medications, 12% reported deciding not to take medicines that do not make them feel better. These findings suggest that patients may benefit from improved communication and education about the value of treatment recommendations to their health outcomes.

Patients also noted that vision and/or hearing impairments are significant barriers to understanding directions from their health care providers, though renal professionals did not identify this a barrier to adherence. However,

33% of professionals cited language barriers as a reason patients missed dialysis appointments, and 24% of providers reported that language barriers prevent ESRD patients from asking questions about their treatment. This reveals a need for improved, culturally relevant patient education in multiple languages, and ensuring that providers have the time and resources they need to adequately support patient adherence.

The survey also showed that non-medical caregivers, such as family and friends, can help support patient adherence to recommended diets. Both patient and professional survey respondents said that help from family with food purchasing and preparation can lead to better management of diet and fluid intake requirements. Patients who reported nonadherence typically lacked strong support networks that could assist not only with preparing ESRD-diet-friendly food, but also with decision-making, setting and attending medical appointments, ensuring transportation, and deciphering complicated medication regimens.

STRATEGIES AND TOOLS TO IMPROVE ADHERENCE

The survey also was designed to gain insight into strategies that could be effective in helping patients be adherent to their treatment regimens.

When asked to identify tools or strategies that would be helpful for managing their care, 74% of patients said working with a dietitian, 56% pointed to printed health materials, and 53% said using a planner or calendar to help organize their care would be helpful (34% of patients were already using a planner/calendar). Some individuals favored watching videos (33%), getting text messages and reminders (31%), taking online or in-person classes (29%), using mobile apps (24%), joining a peer group or online group (22%), using a "points" or loyalty rewards program (21%), and visual reminders like magnets and door hangers (21%).

Patients aged 18–39 were more interested in using a planner to organize their dialysis sessions and other health appointments (66%) than patients who were over 60 years of age (49%). These younger patients were also more interested in using digital and mobile technology for receiving text message reminders about their appointments and medications (49% vs. 21% for age 60+) and using mobile apps (49% vs. 15% for age 60+).

Patients and renal professionals agreed on the need for improved communication in their relationship. Patients said they prefer to talk directly to health professionals instead of reading information provided (18%); and 18% of health professionals believe that patients do not understand the literature that they provide. Among all contributing factors to lack of adherence, renal professionals

commonly expressed the need for more resources to provide better education to patients.

Based on the information revealed by the American Kidney Fund Adherence Survey, AKF has begun developing programs, educational tools and new materials designed to improve adherence. New adherence-supportive health initiatives implemented by AKF in recent months include:

- FIRST30, a program that guides patients new to dialysis through the life changes and common challenges which typically occur over the first 30 days of dialysis treatment.
[KidneyFund.org/first30](https://www.kidneyfund.org/first30)
- “Managing Hyperphosphatemia,” a new professional education course focusing on the importance of phosphorus in the ESRD diet, was added to AKF’s lineup of free online continuing education courses.
[KidneyFund.org/onlinecourses](https://www.kidneyfund.org/onlinecourses)
- A partnership with Cricket Health provided 100 AKF patients with free access to Cricket Health’s award-winning online kidney care platform to help them make informed decisions regarding ongoing disease management and treatment options.
- An engaging series of videos in which a dietitian explains to patients how phosphorous affects their bone health and how to manage their phosphorous intake.
- An infographic on how kidneys keep bones healthy, including information on limiting phosphorus in the diet. Additional diet-related infographics are planned and will be made available to renal dietitians as reference tools for patients.
[KidneyFund.org/infographics](https://www.kidneyfund.org/infographics)

- An infographic with tips on staying hydrated while limiting fluid consumption was created and is now part of the Mayo Clinic’s health resources library for nephrology offices.
[KidneyFund.org/infographics](https://www.kidneyfund.org/infographics)
- The American Kidney Fund Dialysis Planner, a comprehensive calendar, reference and education tool, was distributed to 47,000 dialysis patients at their dialysis facilities.
- Webinars aimed at patients, caregivers, and health professionals on relevant kidney disease topics are held each month and archived for on-demand viewing.
[KidneyFund.org/webinars](https://www.kidneyfund.org/webinars)

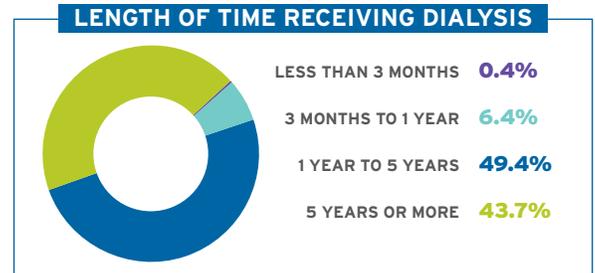
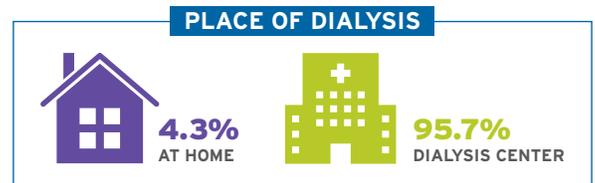
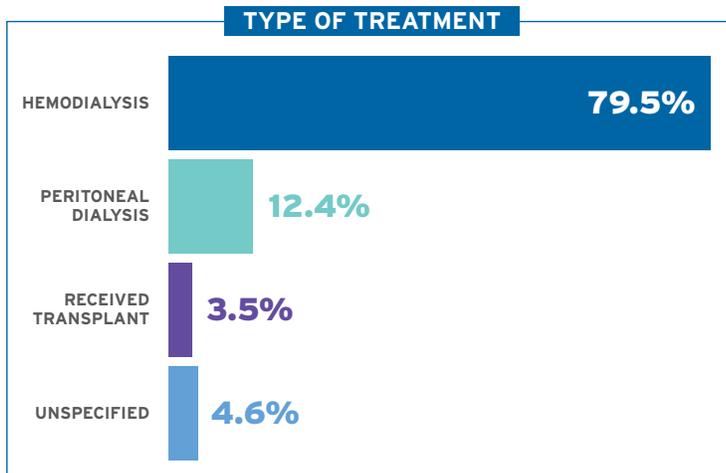
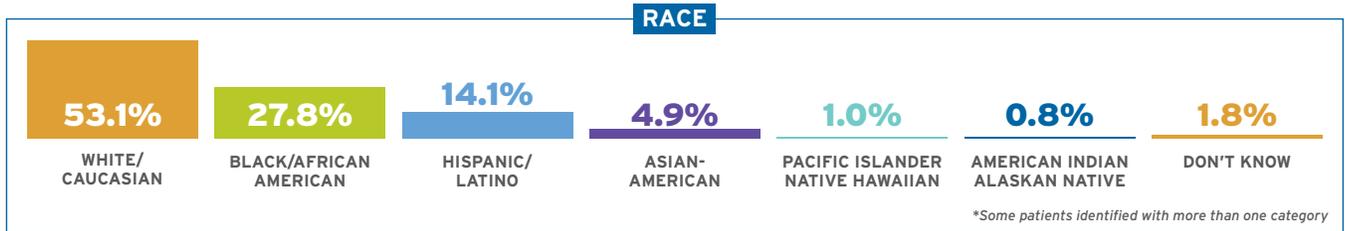
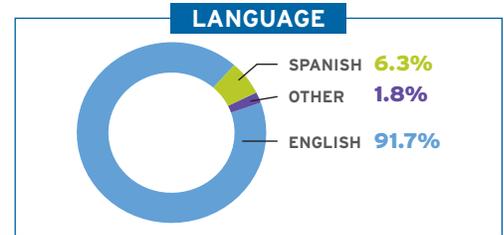
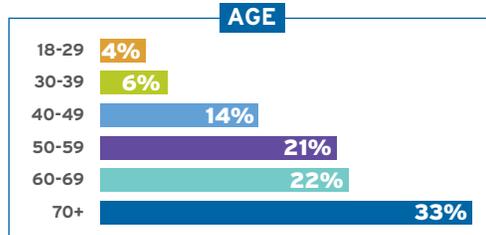
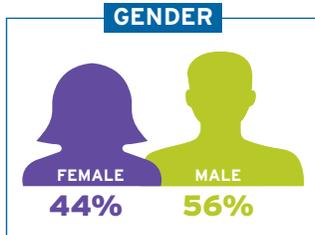
As a patient-centered nonprofit, the American Kidney Fund hopes that this survey will stimulate conversation and further research into barriers to patient adherence, as well as help foster the continual development of effective strategies and tools to improve it.

ACKNOWLEDGMENTS

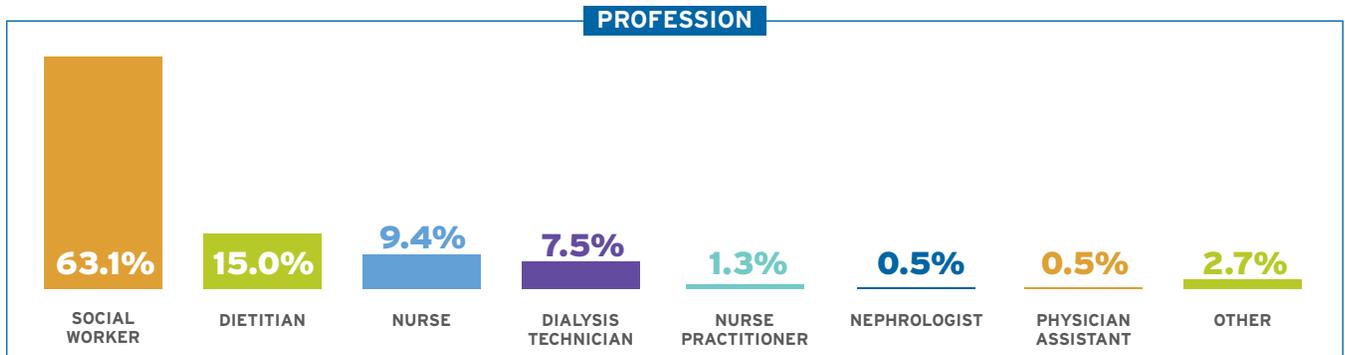
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SURVEY PARTICIPANTS

PATIENTS



HEALTH PROFESSIONALS



*The term "health professional" is used in this report to denote clinicians who provide direct medical care: e.g., physicians, nurses, physician assistants and dialysis technicians, and non-clinicians: e.g., social workers, dietitians and facility managers.



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