ESRD Needs Assessment Survey Results, Fall 2014

BACKGROUND.

Incorporating dialysis for treatment of end-stage renal disease (ESRD) involves drastic changes in a patient's life. In-center treatments at community-based centers typically involve new and time-consuming schedules of being dialyzed for three to four hours, approximately three times a week. In order to help patients with this transition, facilities provide patients with education about chronic kidney disease, infection prevention, and how to maintain a healthy lifestyle, as well as addressing social needs and services such as transportation to the clinic, financial burdens, and emotional challenges.

To help address ESRD patient needs in Arizona, in 2013 the Arizona Department of Health Services (ADHS) Division of Licensing Services and the Healthcare-Associated Infection (HAI) program started the ADVICE collaborative (Arizona Developing Value through Innovation and Communication with ESRD providers) to build strategic partnerships between dialysis providers, ESRD networks, and public health professionals and to stimulate and support significant improvement in infection control in dialysis care.

The Arizona HAI Advisory Committee's ESRD Subcommittee developed an anonymous **electronic survey** to assess ESRD facilities' **patient education practices** and their **perceptions of the remaining needs** throughout Arizona. The survey was conducted from September 5, 2014 to October 13, 2014.

OBJECTIVES.

Assess ESRD facilities' perceptions of:
1. Patient education needs
2. Social service needs

METHODOLOGY.

With the assistance of the Intermountain End-Stage Renal Disease Network 15, the 24-question web-based survey was distributed via e-mail to 117 ESRD facilities across Arizona on September 5, 2014. Facilities were given a 3-week timeframe to respond by September 29, 2014. A reminder was sent to ESRD facilities by Intermountain End-Stage Renal Disease Network 15 on September 29, 2014 and the survey deadline was extended to October 13, 2014. The electronic survey was open for a total of 5 weeks. Questions 1 through 15 were to assess respondents' perceptions of patient education needs. Questions 16 through 24 were to assess the perceptions of the social needs of the patients.

RESPONSE RATE.

The survey was sent to a total of 117 ESRD facilities. 37 facilities responded[†], yielding a 32% response rate.

[†] Unless it is specifically noted in the survey results section, all of the responding facilities (N=37) filled out each question in the survey.

[‡] Transportation was not specifically asked about in this question.

SURVEY RESULTS.

A. Facilities' Patient Education Practices and Perceived Needs

New patient education materials

All facilities report that patients that are new to the dialysis facility are offered a new patient orientation packet. The table below lists the topics covered in new patient orientation packets by the proportion of facilities that cover those topics.

Topics covered in new patient education material‡

More than 90% of facilities covered the following topics	**80%-89%** of facilities covered the following topics	**70%-79%** of facilities covered the following topics	**Less than 70%** of facilities covered the following topics
Infection Prevention	ESRD/Chronic Kidney Disease (CKD)	Insurance	Medical terminology
Safety	Fluid restriction	Support/Counselling	Advance directives and living wills
Types of dialysis	Transplant		Grievance procedures
Nutrition	Risk and benefits of treatment		Other comorbidities such as diabetes
	Emergency preparedness		Laboratory testing
	Medications		

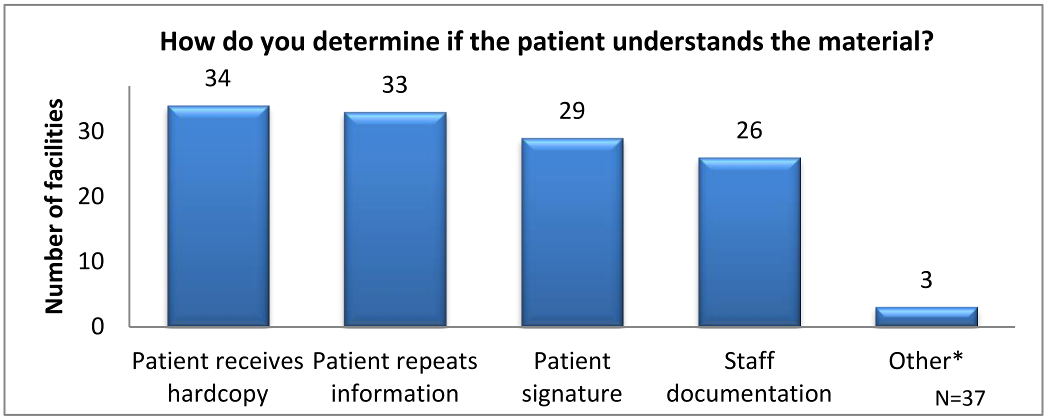
Facilities were asked to list the resources that they use for their new patient orientation packets.

- Thirty-three clinics (89%) report that the information given to patients is facility-specific.
- Eight clinics (22%) stated that they use the ESRD Network: New Patient Orientation packet.
- Other resources for patient education include books/booklets (*Living Well with Kidney Disease*, *IMPACT-First 90 Days of Dialysis* from DaVita; *RightStart* from Fresenius Medical Care) Medicare and CDC resources, and Emergency Preparedness resources from the ESRD Network.

Facilities were asked if there was any information not covered in the new patient orientation packet that could be beneficial to the patient. The responses were categorized below:

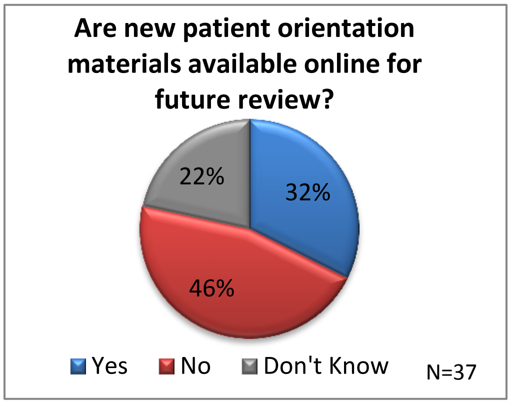
Medical issues related to ESRD	Social concerns and services
Sleep issues	Transportation
Options other than dialysis (e.g., hospice)	Family resources for support groups
ESRD prevention	Emergency preparedness
Medical terminology	

All facilities stated that the staff ensures that the patient understands the educational material in the new patient orientation packets. The most common methods to verify patient comprehension are by **providing a hardcopy of the information** and **asking the patient to repeat the information,** as shown below in the graph.



* Other responses include: 'family receives education so that they can reinforce the information as well', 'offer opportunities to ask questions', and 'teach-back/return demonstration'.

Only 12 (32%) facilities stated that new patient orientation packets are available online; the majority of facilities that responded to this survey either **did not know if the new orientation packets were available online,** or **stated that they were not available online**.



Additional educational resources for ESRD patients

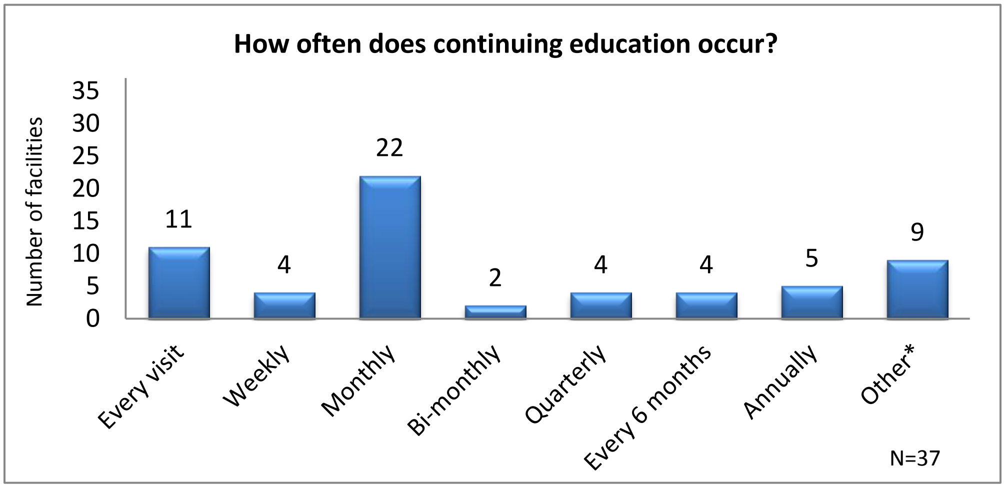
Facilities were asked if their patient population would benefit from more education and resources in specific areas. Of 36 respondents:

- The most commonly chosen areas for additional resources were **death by non-compliance** (28 facilities, 78%), **fluid intake** (20 facilities, 56%), and **nutrition** (18 facilities, 50%).

Other areas of interest included more information about medications (12 facilities, 33%), infection prevention (11 facilities, 31%), and patient safety (9 facilities, 25%).

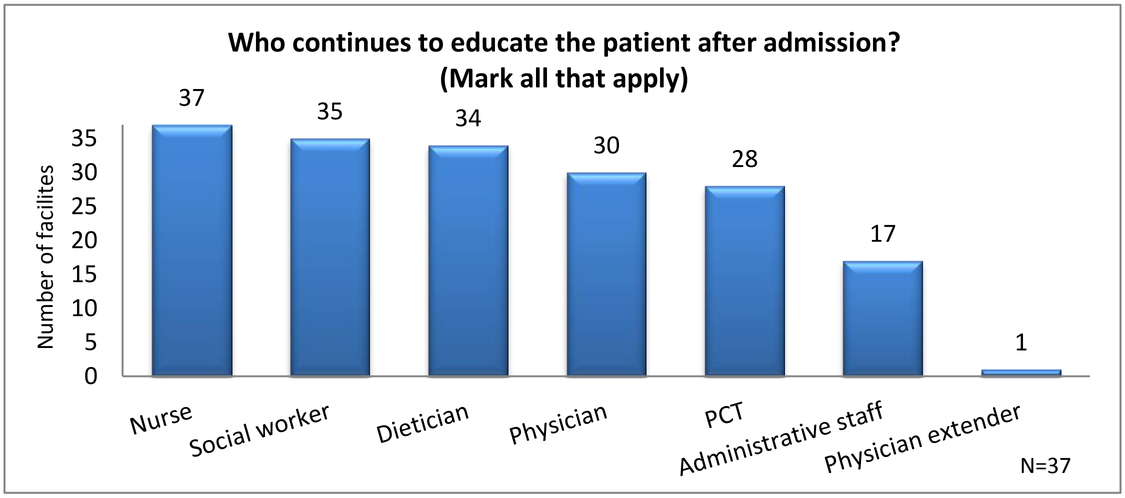
Continuing education for ESRD patients

Facilities stated that ESRD patient education material is reviewed with patients at various intervals. The majority of facilities **reviews ESRD patient education material on a monthly basis**; see the chart below for more specific information on frequency of continuing education.



*Other responses include: 'frequency depends on type of education', and 'as needed based on the patient's needs'

At all facilities, **nurses take part in continuing to educate the patient** after admission. Social workers, dieticians, physicians, and patient care technicians (PCTs) also provide education to the patients at the majority of facilities. Administrative staff is less likely to provide education, as shown in the graph below.

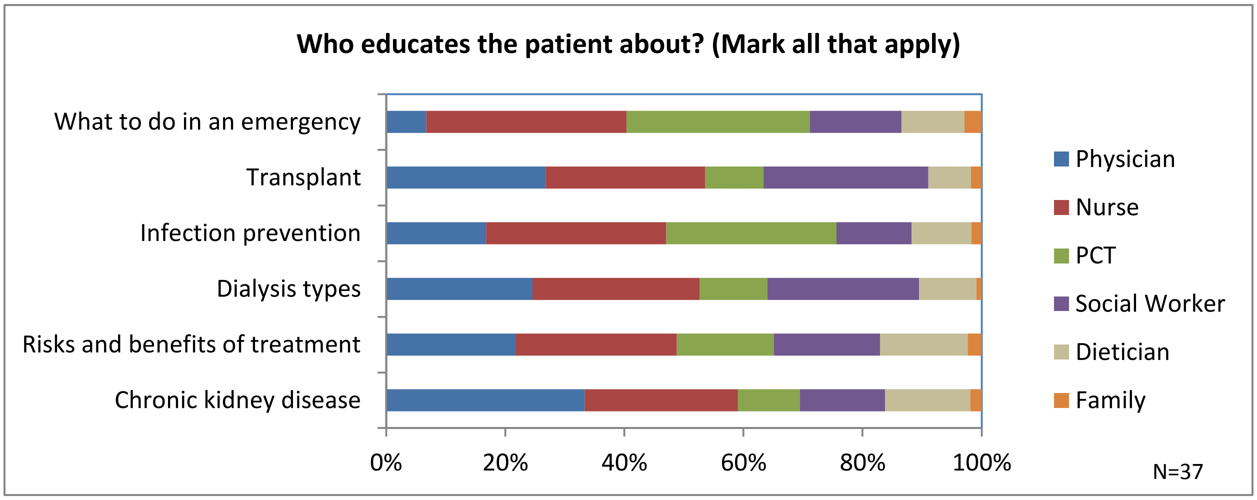


Facilities were also asked about the topics of education provided by different groups of persons. **Nurses** were consistently identified as educating patients about a range of ESRD topics; family members were the least likely to be identified as providing education. Additionally, different staff members were found to educate patients about ESRD topics according to their specialty:

- **Physicians** educated patients most frequently about chronic kidney disease and transplants.
- **PCTs** educated patients most frequently about what to do in an emergency and infection prevention.

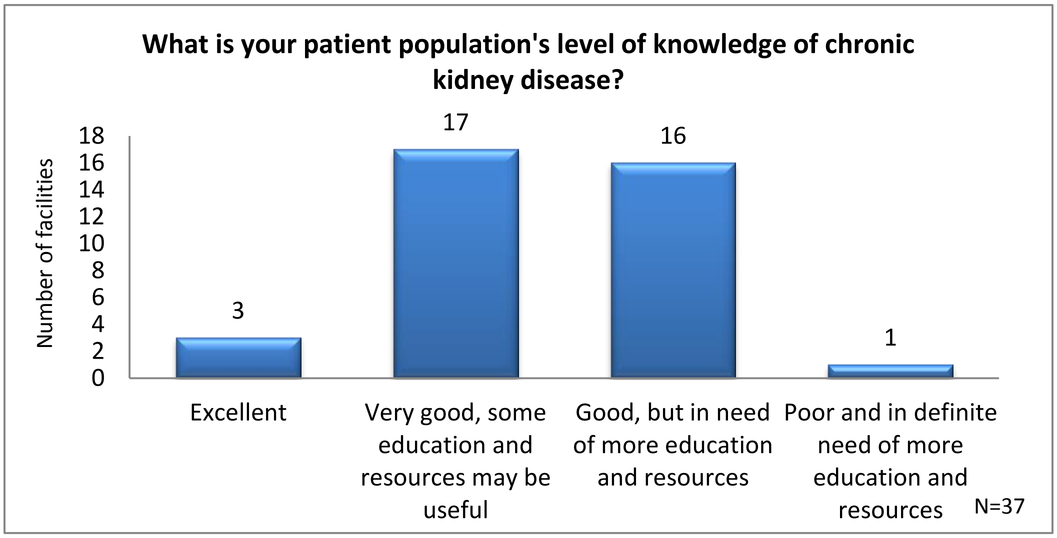
- **Social workers** educated patients most frequently about dialysis types and transplants.
- **Dieticians** educated patients most frequently about risks and benefits of treatment and chronic kidney disease.

Overall, education about the risks and benefits of treatment was provided more equally by all staff members, as shown in the graph below.



ESRD patient knowledge levels

Overall, 36 facilities (97%) believe that their patient population's **level of knowledge of chronic kidney disease is good, very good, or excellent**. Even though the perceived patient population's education level is high, facilities also report that they **need to use more educational materials**, with 34 facilities (92%) stating that education resources would be useful for their patient population.

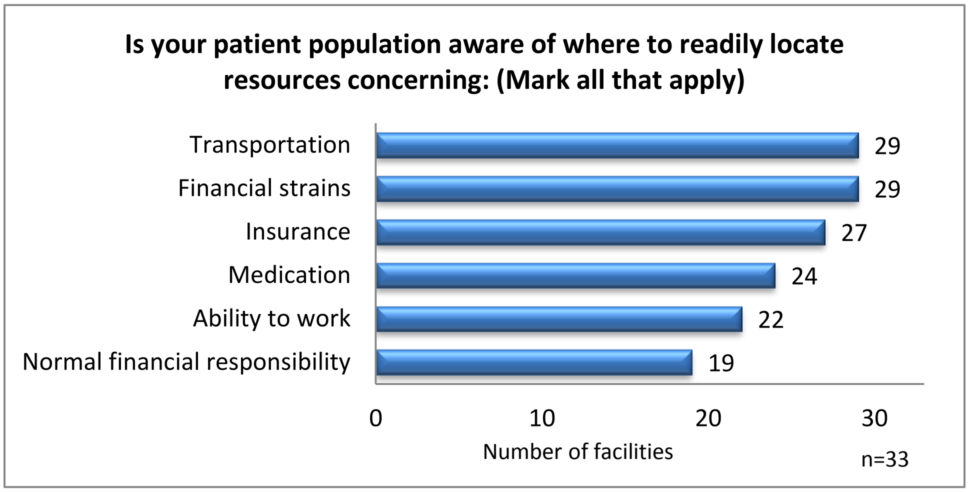


B. Social Concerns and Services

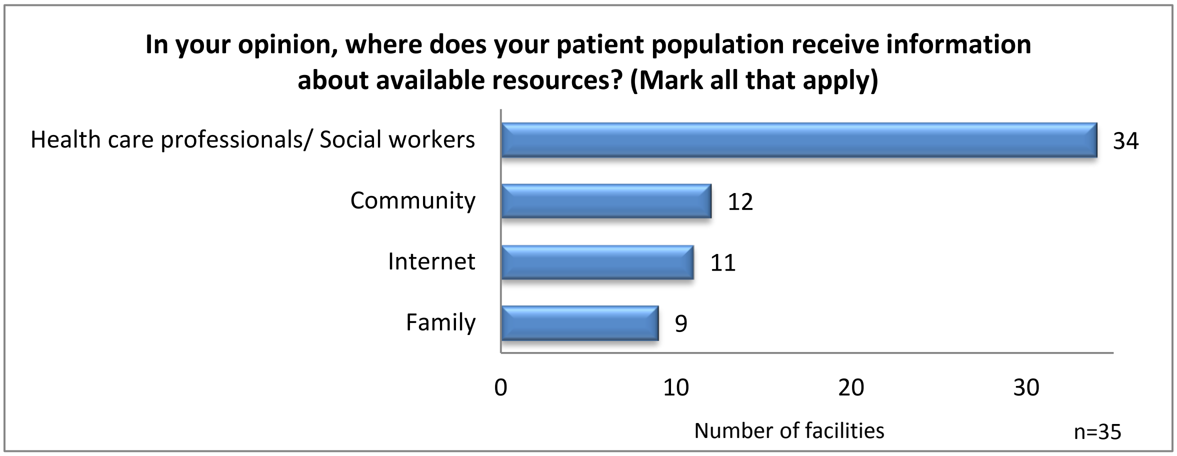
All facilities were asked their opinion about social concerns and services of their ESRD patients and families.

Dissemination of resources regarding social concerns and services

Facilities were asked to identify which resources regarding social concerns and services patients could readily identify. Of the 33 responding facilities, resources about **transportation** and **financial strains**[§] ranked the highest with 29 facilities (88%) stating that **patients could readily locate these resources**. The **ability to work** (22 facilities, 67%) and **normal financial responsibilty**[α] (19 facilities, 58%) were identified the least frequently as resources that patients could easily locate.



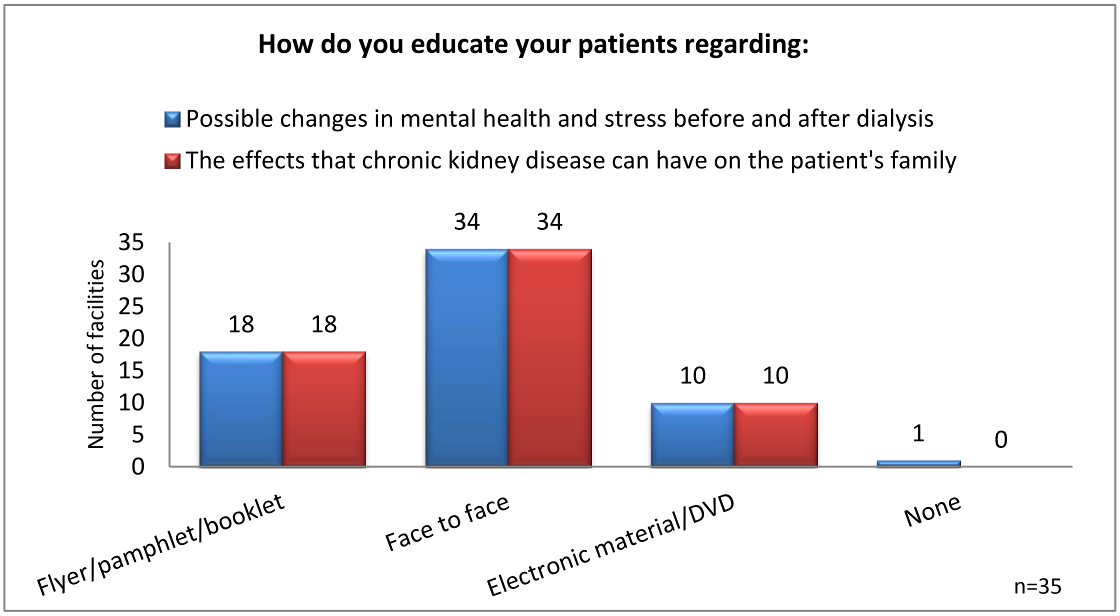
Most facilities indicated that they believe their patients **receive information about resources regarding social concerns and services from healthcare workers** (34 facilities, 97%), with lower responses for other sources of information (among 35 responding facilities).



[§]"Financial strains" are defined as financial cost and situations that arise after starting dialysis and are a negative impact on the patient. For example: transportation, child/day care, chronic kidney disease, diet, inability to work due to chronic kidney disease, etc.

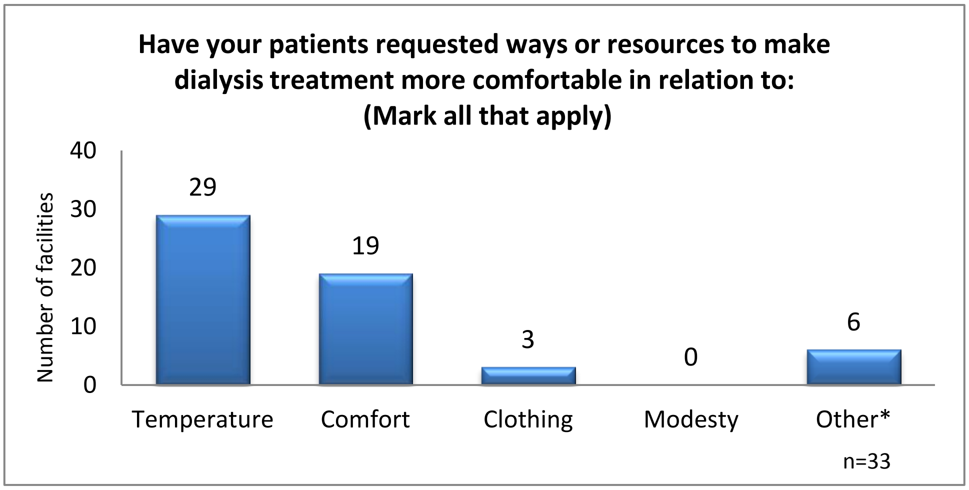
[α] "Normal financial responsibility" is defined as the normal cost of living that existed prior to being on dialysis.

Facilities were asked how they educate their patient population concerning two areas in particular: possible changes in mental health and stress before and after dialysis, and the effects that chronic kidney disease can have on the patient's family. Among the 35 responding facilities, **education was administered face-to-face at almost all facilities** for both topics (34 facilities, 97%) as well as using printed material (18 facilities, 51%) and electronic material (10 facilities, 29%).



Patient comfort during dialysis treatments

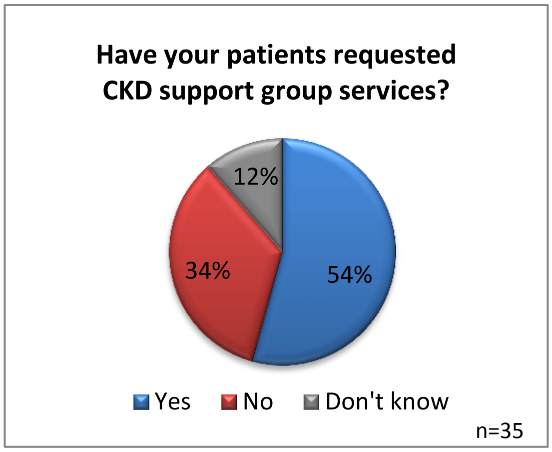
Of 33 respondents, the most facilities report that patients have requested **temperature** (29 facilities, 88%) and **comfort** (19 facilities, 58%) as areas to improve for **making dialysis treatment more comfortable**.

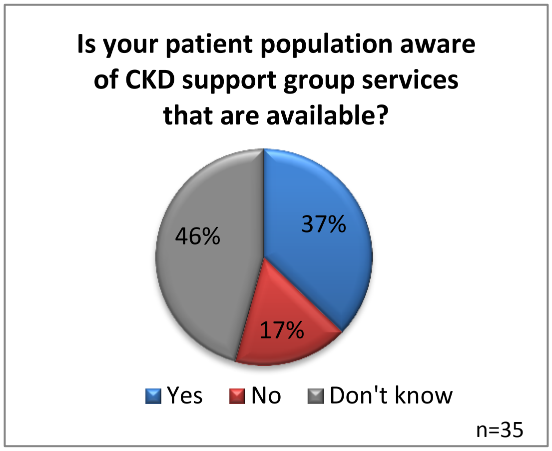


* Other responses include: television, internet, dialysis chairs, reduction in noise level, and sleeping during treatment.

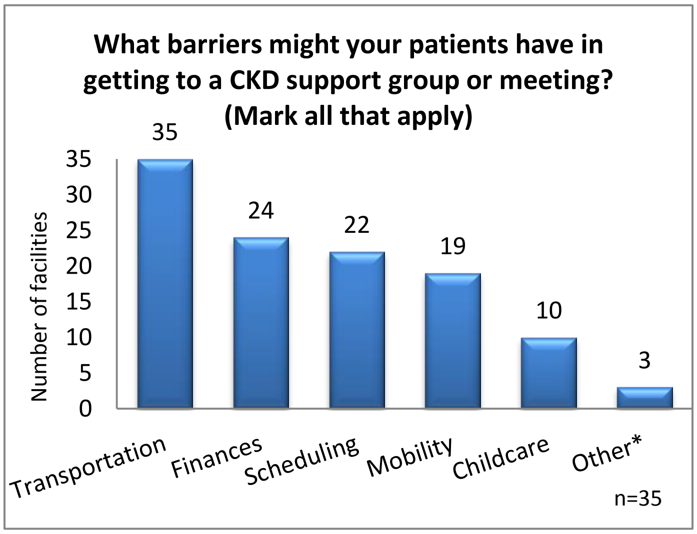
Family and/or group chronic kidney disease support services

Facilities were asked about patient interest, awareness, and perceived barriers that patients may have accessing family and/or group chronic kidney disease (CKD) support services. Among 35 respondents, the majority of facilities (19 facilities, 54%) stated that **patients have requested support group services**. However, a little less than half of the facilities (16 facilities, 46%) were **unsure if their patients are aware of CKD support services** that are available.



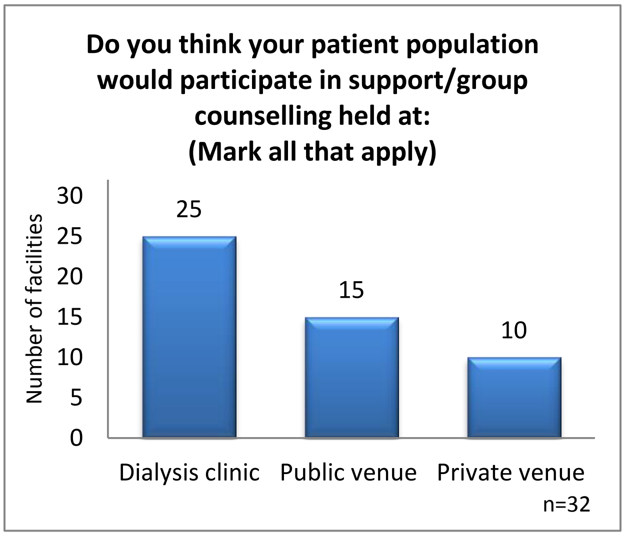


Of 35 responding facilities, **transportation** (35 facilities, 100%) and **finances** (24 facilities, 69%) were identified as the most likely **perceived barriers** that patients may have **accessing CKD support services**.



* Other responses include: cultural beliefs, unavailable support groups, and lack of interest.

Among 32 responding facilities, it was perceived that holding **support/group counselling at the dialysis clinic** might encourage participation.



Discussion.

Based on results from the ADHS ESRD Needs Assessment Survey (Fall 2014), the majority of **patient education needs at ESRD facilities in Arizona have been met**, with almost all facilities stating that their population's level of knowledge of chronic kidney disease is good, very good, or excellent. Even though the perceived patient population's education level is high, there is still a need for developing educational materials and evaluating the methods in distributing these resources.

1. *Patient Education Needs*

The following ESRD patient education topics have been identified as a priority for development of additional resources: **death by non-compliance, fluid intake,** and **nutrition**. Some facilities report the need to include additional materials in their new patient orientation packets such as **sleep issues, options other than dialysis (e.g., hospice), ESRD prevention,** and **medical terminology**. The following topics are not covered often in new orientation packets, but may be of interest for future resource development: advance directives and living wills, grievance procedures, comorbidities, and laboratory testing.

Nurses, social workers, and dieticians participate most frequently in continuing to educate the patient after admission. Nurses consistently educate patients about a variety of ESRD topics while facilities perceived **family members** as being the least involved in providing education. Additionally, different staff members have been found to educate patients about ESRD topics according to their specialty:

- **Physicians**-chronic kidney disease and transplants
- **Patient Care Technicians (PCTs)**-what to do in an emergency and infection prevention
- **Social workers**-dialysis types and transplants.

Although **dieticians** are found to provide more continuing education than physicians and PCTs, it is not clear from the survey results which education topics dieticians take the lead on since options such as 'nutrition' and 'fluid-intake' were not included in the survey.

2. *Social Service Needs*

Social concerns and services for ESRD patients and families were also assessed in the ADHS ESRD Needs Assessment Survey (Fall 2014). Almost all facilities report that patients can easily access materials about **transportation** (to dialysis appointments) and **financial strains** while only about two-thirds thought their patients could readily locate resources about the **ability to work** or **normal financial responsibility**.

In order to make dialysis treatment more comfortable for ESRD patients, focusing on **temperature** and **comfort** have been identified as priorities. For facilities interested in setting up support/group counselling, major barriers for patient participation include **transportation** (to CKD support groups), and **finances**. In order to encourage participation, facilities noted that CKD support groups could be held at dialysis clinics instead of public or private venues.

3. *Limitations*

Although 37 ESRD facilities in Arizona participated in this survey, the overall response rate was low (32%). This low response rate may lead to a sampling bias. For example, facilities that responded may have been more heavily involved in patient education than those facilities that did not respond to the survey. These results are dependent on facilities' responses to provide data that will push Arizona specific interventions and projects.

Another limitation of this study is that some questions were better targeted for ESRD patients to answer instead of the ESRD facilities. For example, facilities know that they give resources, but may not know where else the patient gets information from. Facilities may not have known the answers to some of the questions about patient educational resources.

4. *Future recommendations*

ESRD subcommittee members identified the following recommendations based on these survey results:

- Asking for feedback from all ESRD facilities
- Having a 'show and tell' with facilities by going over their educational resources and orientation packets as well as how they teach and to what education level they teach to
- Reviewing available educational programs from the state and national levels
- Defining more clearly which infection prevention topics are covered
- Creating a monthly educational calendar
- Developing survey requirements for education of the patient/ families

Conclusion.

Results from this survey can guide recommendations and next steps to provide better care for ESRD patients in Arizona.