

# Incongruence in Perception: Health literacy in people receiving hemodialysis

“I can’t ever figure out that I didn’t understand”

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Kingston Health  
Sciences Centre

Centre des sciences de  
la santé de Kingston



# Health Literacy and Patients with Chronic Kidney Disease -What's the evidence?

- Inadequate health literacy in people with chronic kidney disease (CKD) is associated with poorer disease management and greater complications (Lambert, Mullan, Mansfield & Lonergan, 2015)
- Patients receiving hemodialysis who have limited health literacy are more likely to miss dialysis treatments, use emergency care, and be hospitalized (Green et. Al, 2013; Dageforde & Cavanaugh, 2015)
- New patients referred to a renal outpatient department had poor knowledge about kidney disease. For most patients, education programs need to be targeted at a simplistic level (Burke, Kapojos, Sammartino, & Gray, 2014)
- There is a significant association between health literacy and eGFR. Providers should use health literacy-tailored communication strategies with CKD patients (Devraj et. al, 2015)

So what does health literacy look like for patients receiving dialysis at KHSC?



## BRIEF: Health Literacy Screening Tool

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Please circle the answer that best represents your response.

1. How often do you have someone help you read hospital materials?
  1. Always
  2. Often
  3. Sometimes
  4. Occasionally
  5. Never
  
2. How often do you have problems learning about your medical condition because of difficulty understanding written information?
  1. Always
  2. Often
  3. Sometimes
  4. Occasionally
  5. Never
  
3. How often do you have a problem understanding what is told to you about your medical condition?
  1. Always
  2. Often
  3. Sometimes
  4. Occasionally
  5. Never
  
4. How confident are you filling out medical forms by yourself?
  1. Not at all
  2. A little bit
  3. Somewhat
  4. Quite a bit
  5. Extremely

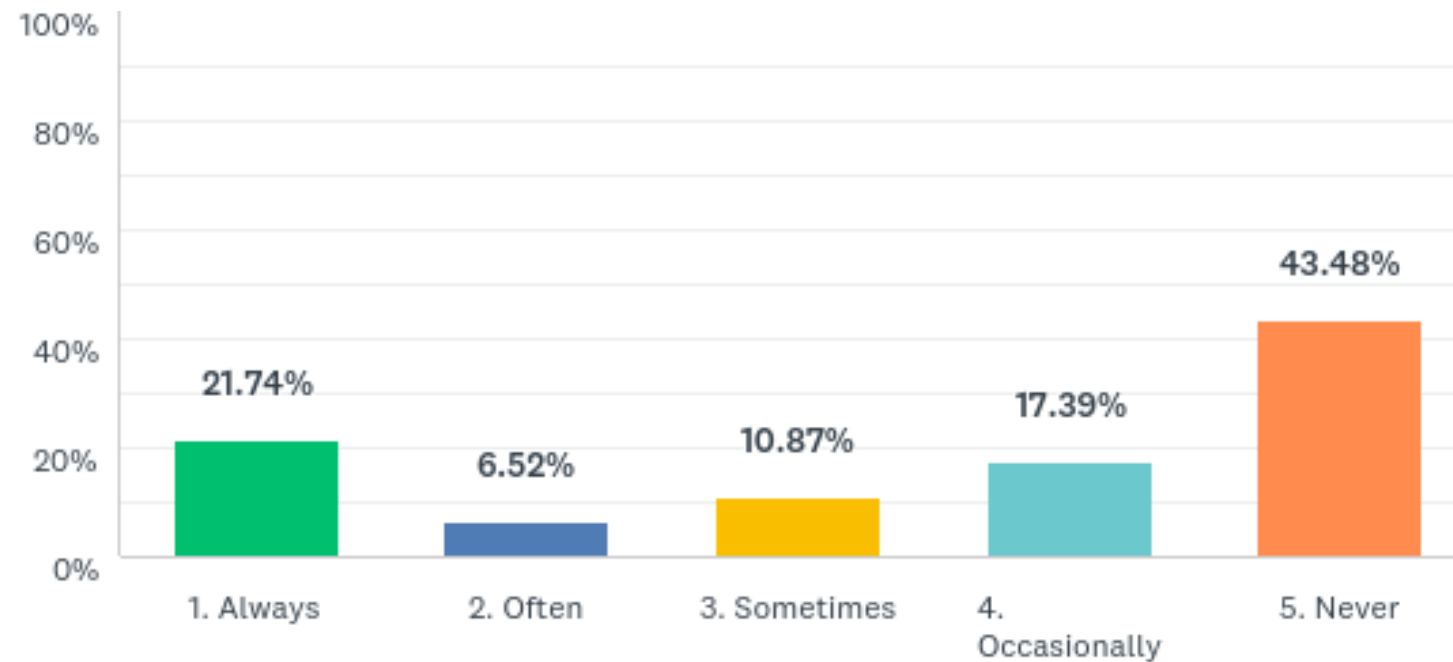
Clinicians can ask patients these four questions to determine their patients' health literacy level (the degree to which one can read, understand, exchange, and use health information and resources). Each item is worth 1 to 5 points depending on their response (as seen in numbers to the left of the answer options). Add the values for the four responses to get a total score, which can range from a minimum of 4 to a maximum to 20. To interpret [scores](#) refer to the following table:

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BRIEF	Score	Skills and Abilities
Limited	<b>4-12</b>	Not able to read most low literacy health materials; will need repeated oral instructions; materials should be composed of illustrations or video tapes. Will need low literacy materials; may not be able to read a prescription label.
Marginal	<b>13-16</b>	May need assistance; may struggle with patient education materials.
Adequate	<b>17-20</b>	Will be able to read and comprehend most patient education materials.

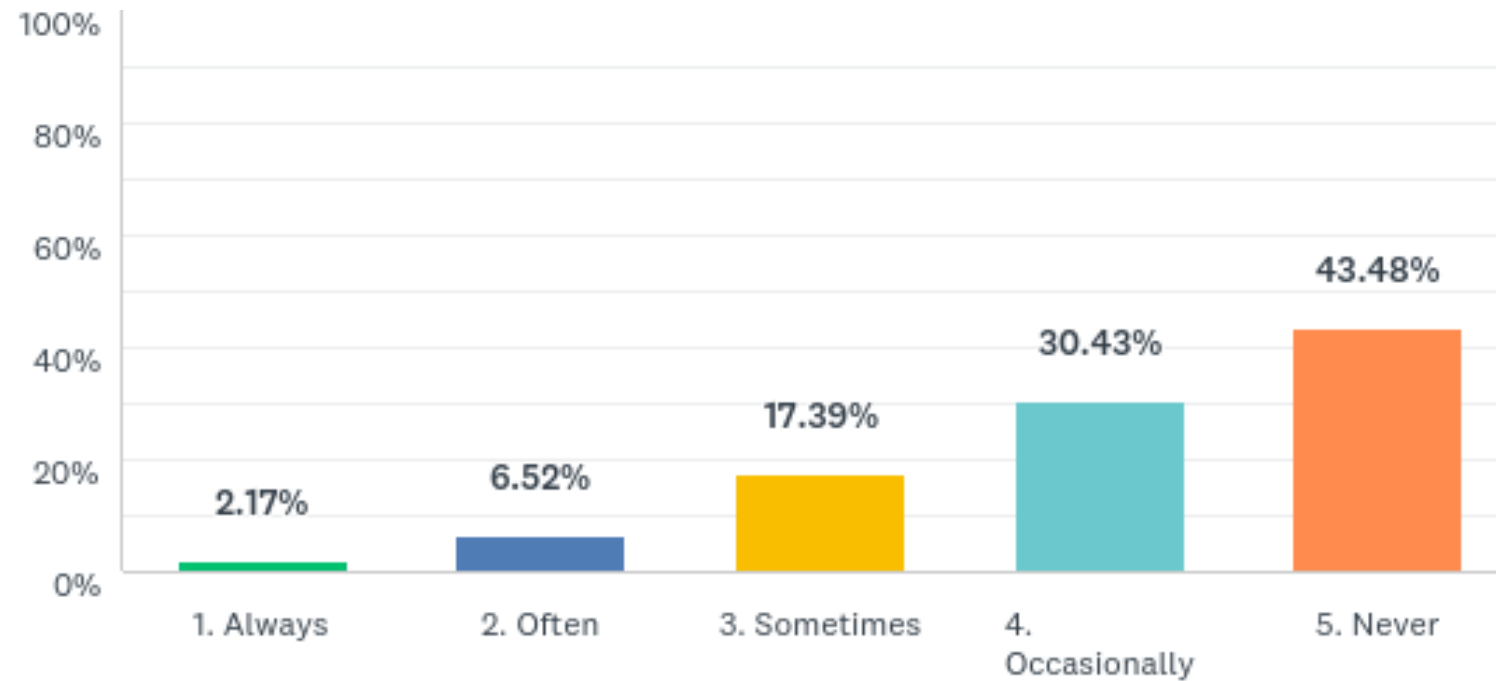
# Q1: How often do you have someone help you read hospital materials?

Answered: 46 Skipped: 0



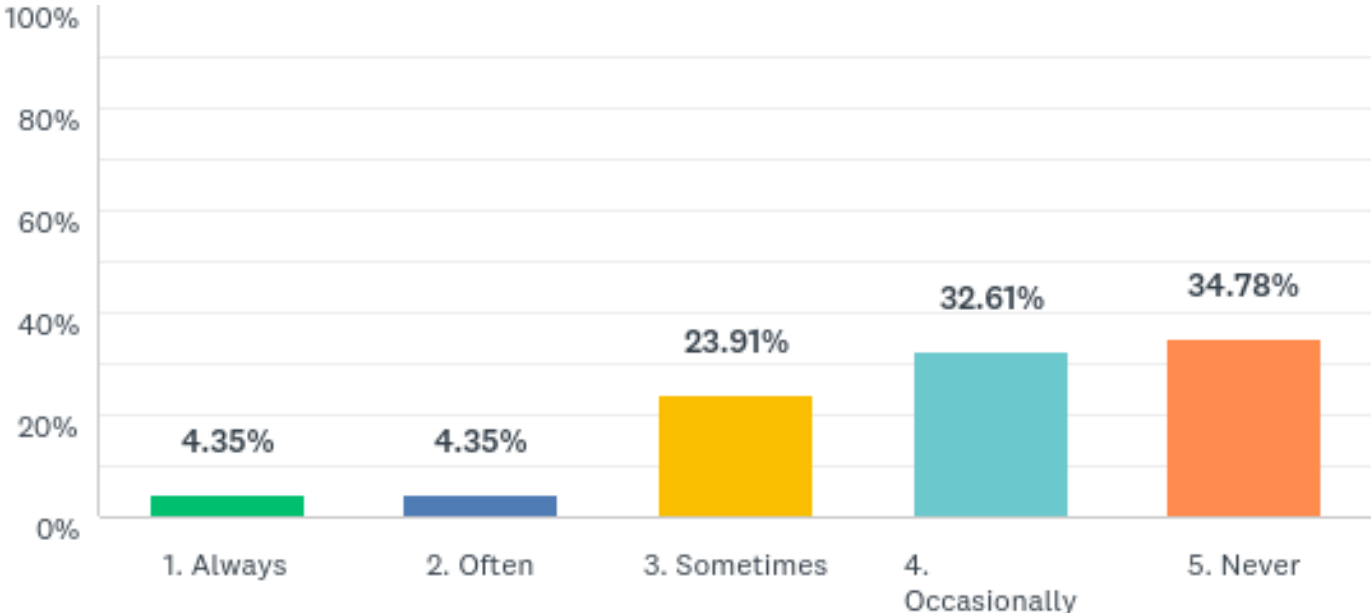
## Q2: How often do you have problems learning about your medical condition because of difficulty understanding written information?

Answered: 46 Skipped: 0



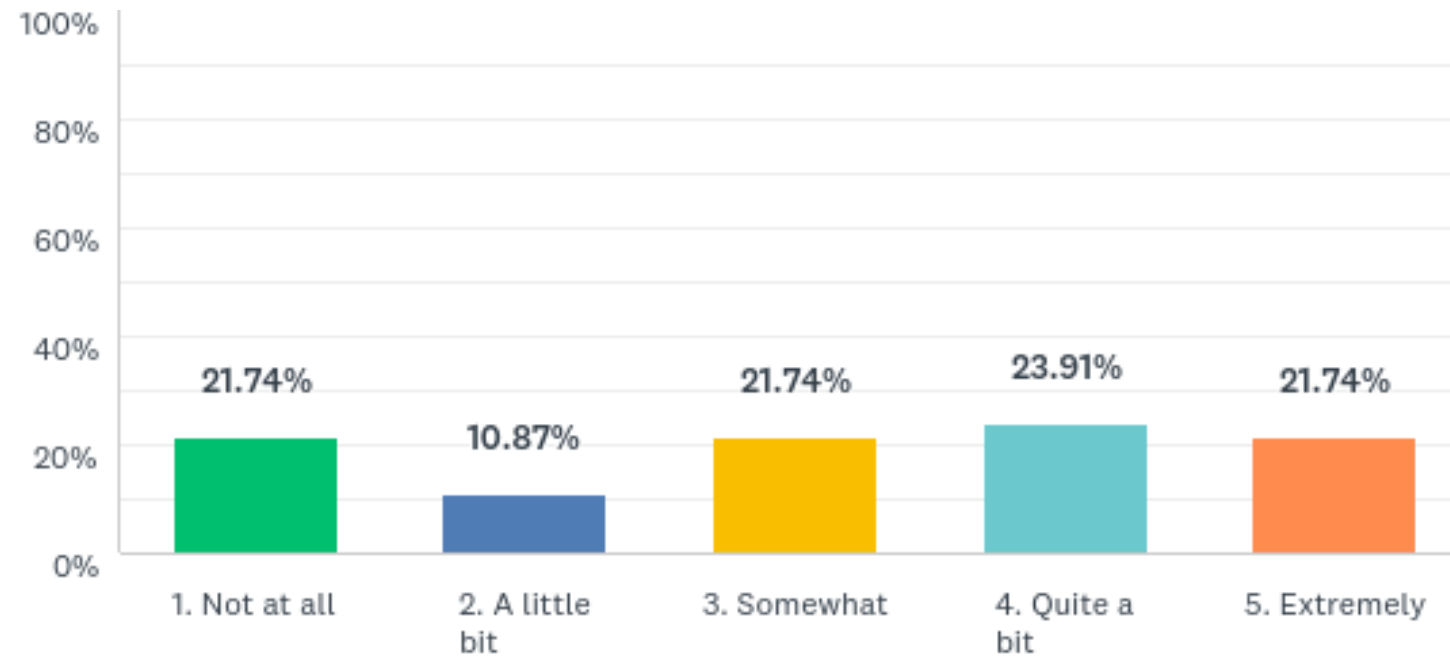
### Q3: How often do you have a problem understanding what is told to you about your medical condition?

Answered: 46 Skipped: 0



## Q4: How confident are you filling out medical forms by yourself?

Answered: 46 Skipped: 0







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**Nutrition Facts**

Serving Size ½ cup  
Servings per container 4

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Amount per serving

Calories 250 Fat Cal 120

---

%DV

**Total Fat** 13g 20%

---

Sat Fat 9g 40%

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**Cholesterol** 28mg 12%

---

**Sodium** 55mg 2%

---

**Total Carbohydrate** 30g 12%

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Dietary Fiber 2g

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Sugars 23g

---

**Protein** 4g 8%

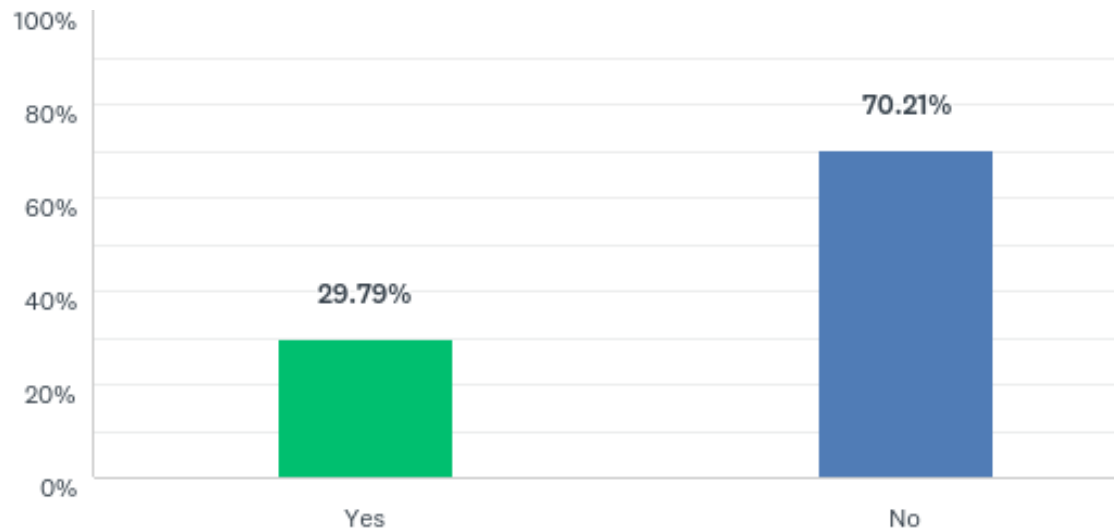
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\*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

**Q1:** If you eat the entire container, how many calories will you eat? Answer correct?

Answered: 47 Skipped: 0



<b>Nutrition Facts</b>			
Serving Size		½ cup	
Servings per container		4	
Amount per serving			
Calories	250	Fat Cal	120
		%DV	
<b>Total Fat</b>	13g		20%
Sat Fat	9g		40%
<b>Cholesterol</b>	28mg		12%
<b>Sodium</b>	55mg		2%
<b>Total Carbohydrate</b>	30g		12%
Dietary Fiber	2g		
Sugars	23g		
<b>Protein</b>	4g		8%

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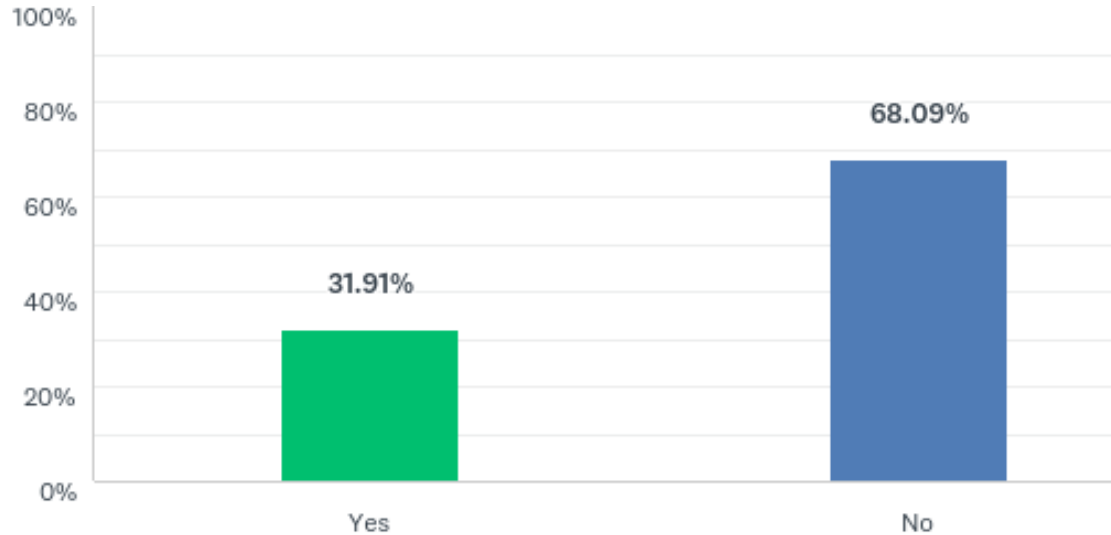
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**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

Q2: If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have? Answer correct?

Answered: 47 Skipped: 0



<b>Nutrition Facts</b>			
Serving Size			½ cup
Servings per container			4
<b>Amount per serving</b>			
Calories	250	Fat Cal	120
<hr/>			
			<b>%DV</b>
<b>Total Fat</b>	13g		20%
Sat Fat	9g		40%
<b>Cholesterol</b>	28mg		12%
<b>Sodium</b>	55mg		2%
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Sugars 23g

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**Protein** 4g 8%

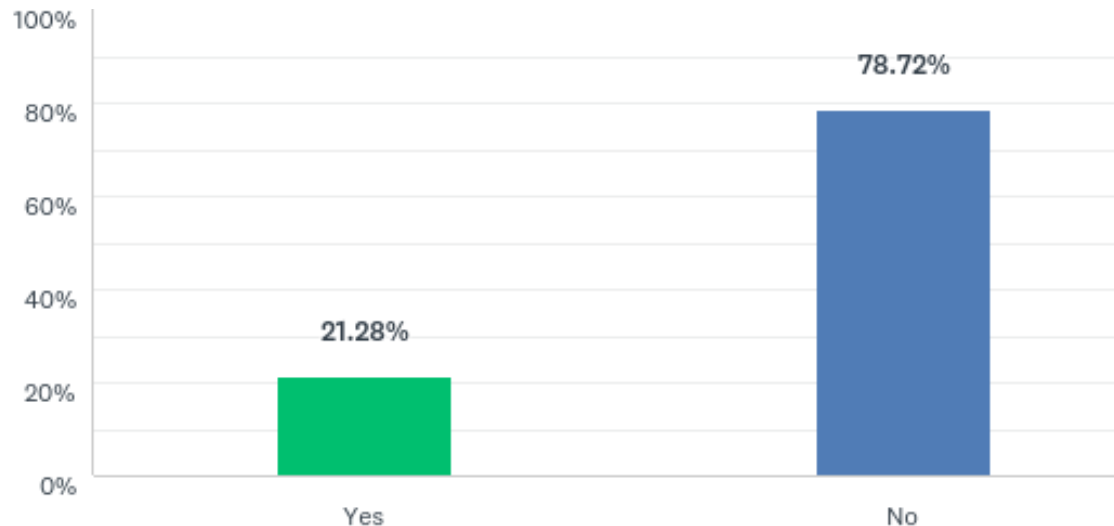
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**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

**Q3:** Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?  
Answer correct?

Answered: 47 Skipped: 0



<b>Nutrition Facts</b>			
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Servings per container		4	
<hr/>			
Amount per serving			
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			%DV
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Sugars 23g

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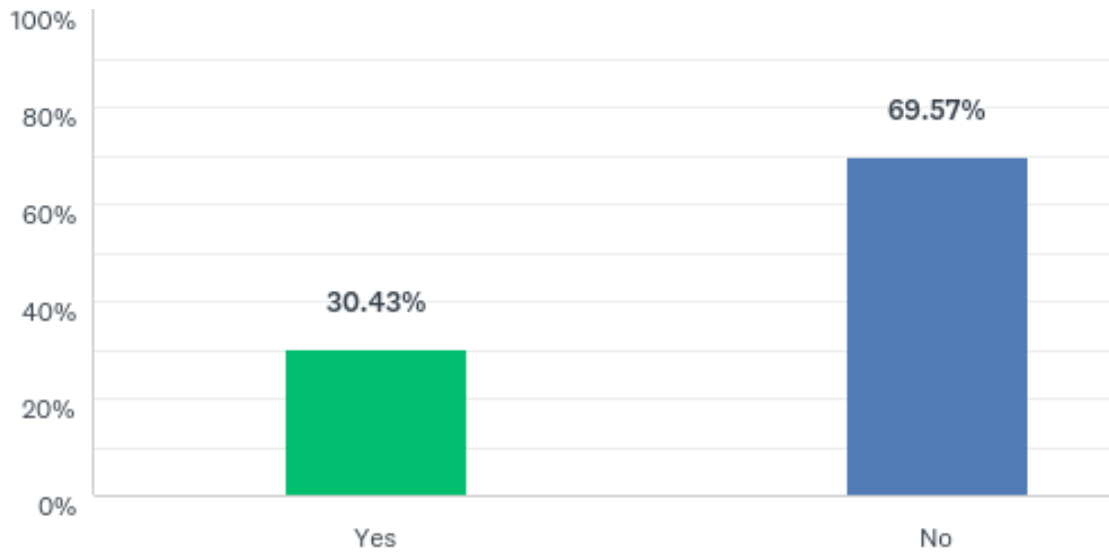
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**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.



**Q4:** If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you eat in one serving? Answer correct?

Answered: 46 Skipped: 1



<b>Nutrition Facts</b>			
Serving Size			½ cup
Servings per container			4
<b>Amount per serving</b>			
Calories	250	Fat Cal	120
<hr/>			
			<b>%DV</b>
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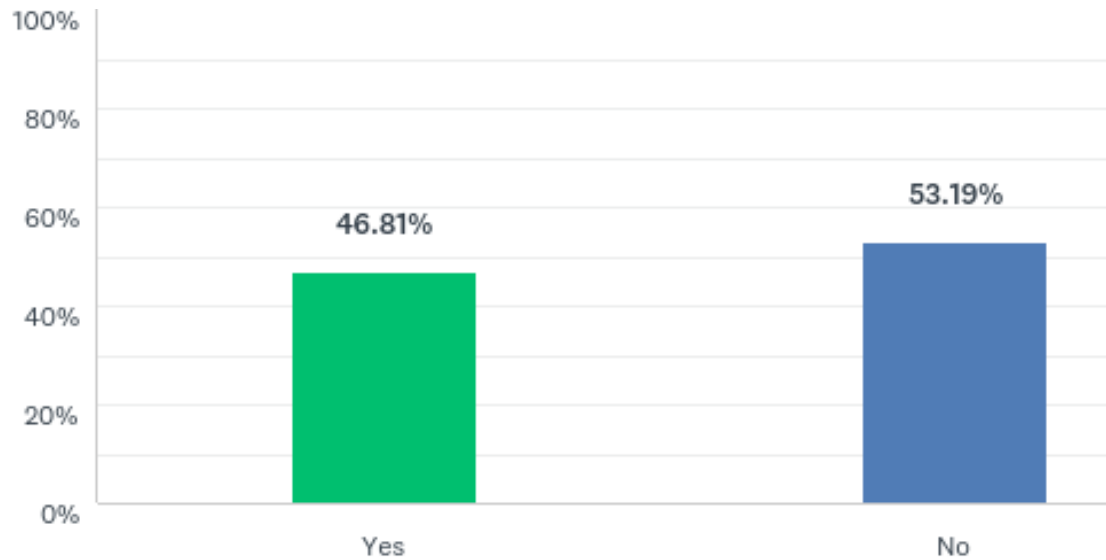
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**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

**Q5:** Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings. Is it safe to eat this ice cream?

Answered: 47 Skipped: 0



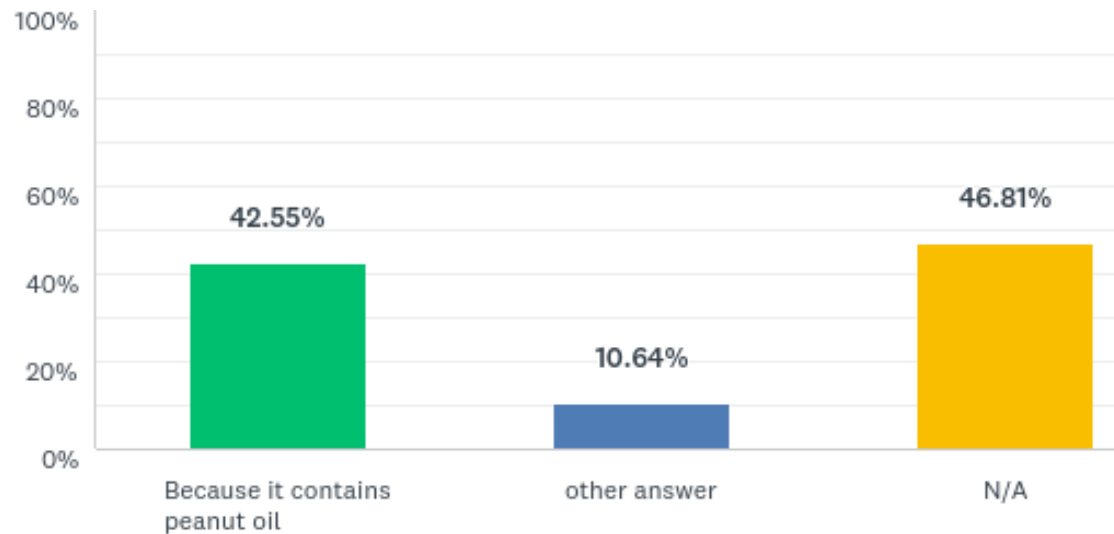
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**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

# Q6: (If patient responds no) Why not?

Answered: 47 Skipped: 0



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<b>Amount per serving</b>			
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# Qualitative Interviews

## Education:

- “I can’t ever figure out that I didn’t understand”
- “When I had to get the bypass, for some reason they call it a cabbage, they were saying the cabbage, and I said, what’s a cabbage”
- “Well, some things I understand and some things I don’t. I just listen that’s all. I just listen to them...just listen. “
- “Oh I’ve got papers at home. I haven’t even read them all”

# Qualitative Interviews

## **Social support:**

- “We just discuss it and move on”
- “We have a cousin and his friend is also a nephrologist”

## **Experience:**

- “We are just dealing with it as we go on”

## **Decision making:**

- “I always need help making decisions about my health”
- “Well when I came to the hospital ... I had decided I am not coming to dialysis. And the doctor said I would die in four days. I didn't understand...”

# Conclusions

- There is incongruence in the perception of health literacy skills amongst patients receiving hemodialysis at KHSC:
  - Personal perception of adequate skills to understand health information and effectively self-manage their chronic disease
  - Patients have a high likelihood of limited health literacy

# Practice Implications

- Equipping providers with the tools to meet the health literacy needs of this population is essential. Strategies to mitigate this incongruence include:
  - Universal health literacy precautions;
  - Plain language;
  - Teach-back; and
  - Organizational policy and preparatory programs that incorporate these strategies as standard of practice.