

# Health literacy in conservatively managed RSC patients

Jessica Stevenson
Renal Supportive Care Dietitian
St George Hospital

## WHAT IS HEALTH LITERACY

The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health (World Health Organisation)



 HL is particularly important where optimal management of disease requires a variety of self-management behaviours.

#### In CKD:

 Execution of recommended treatments is often suboptimal and likely due to patients being tasked with understanding, implementing and maintaining a range of complex recommendations for self-care.



## What is health literacy?



Taylor, D. et al. 2017. Health literacy and patient outcomes in chronic kidney disease: a systematic review. NDT, 20 Nov 2017

Health literacy ax tool	Domain	SR
Short test of function health literacy in adults (S-TOFHLA)	Reading comprehension	10 studies
Rapid Estimate of Adult Health Literacy in Medicine (REALM)	Reading comprehension	14 studies
Brief Health Literacy Screen (BHLS)	<ul> <li>3 questions rated on scale of 1-5</li> <li>- How confident are you filling out forms by yourself?</li> <li>- How often do you have someone help you read hospital materials?</li> <li>- How often do you have problems learning about your medical condition because of difficulty reading hospital materials?</li> </ul>	3 studies
Newest Vital Sign (NVS)	Reading comprehension	4 studies

There is limited published data exploring HL of CKD patients using comprehensive tools which are able to measure multiple dimensions of HL.

# The aim of our study was to evaluate HL in our renal population using a comprehensive tool



## **Health Literacy Questionnaire (HLQ)**

- explores 9 domains that encompass a person's health literacy rather than a single domain.
- captures a wide range of lived experiences of people attempting to engage in understanding, accessing and using health information and health services and is able to provide a reflection of the quality of health and social service provision.
- translated into 19 languages



		Strongly disagne. Disagnee. Agne. Strongly agnee.
1	I feel I have good information about health	
2	I have at least one healthcare provider who knows me well	
3	I can get access to several people who understand and support me	
4	I compare health information from different sources	
5	When I feel ill, the people around me really understand what I am going through	
6	I spend quite a lot of time actively managing my health	
7	When I see new information about health, I check up on whether it is true or not	



		Camot do or always difficult Sometimes difficult Usually easy Always easy
1	Find the right health care	
2	Make sure that healthcare providers understand your problems properly	
3	Find information about health problems	
4	Feel able to discuss your health concerns with a healthcare provider	
5	Confidently fill medical forms in the correct way	
6	Find health information from several different places	
7	Have good discussions about your health with doctors	
8	Get to see the healthcare providers you need to	
9	Accurately follow instructions from healthcare providers	

	Low level of the construct
1. Feeling understood (organisation)	Unable to engage with, or trust, doctors and other healthcare providers as a source of information and/or advice
2. Having sufficient information to manage my health (organisation)	Many gaps in their knowledge and they don't have the information they need to live with and manage their health concerns
3. Actively managing my health (individual)	Don't see their health as their responsibility and regard healthcare as something that is done to them.
4. Social support for health (individual)	Completely alone and unsupported for health.
<b>5. Appraisal of health information</b> (individual)	No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information
6. Ability to actively engage with healthcare providers (individual, organisation)	Passive in their approach to healthcare; accept information without question and are unable to clarify what they do not understand; accept what is offered without seeking to ensure that it meets their needs; Feel unable to share concerns.
7. Navigating the healthcare system (individual, organisation)	Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.
8. Ability to find good health information (individual, organisation)	Cannot access health information when required. Is dependent on others to offer information.
9. Understanding health information well enough to know what to do (individual, organisation)	Has problems understanding any written health information or instructions about treatments or medications.

## Results

#### N=102 patients surveyed

Conservative	RSC-SS	Haemodialys is	Home HD	PD
N=17	N=21	N=48	N=17	N=20

- Overall 50.6% response rate
- 65% male
- 68.2% had completed high school education
- 67.5% spoke English at home

Non-responders were of similar age, gender, country of birth and language spoken at home



Domains 1-5: Scored on a Likert scale of 1-4.

An average score of 3 or above was classified as <u>adequate</u> <u>health literacy</u>

Domains 6-9: Scored on a Likert scale of 1-5.

An average score of 4 or above was classified as <u>adequate</u> <u>health literacy</u>



	Mean (SD)	% classified as having adequate HL
Domain 1	3.29 (0.28)	88%
Domain 2	3.03 (0.31)	76.5%
Domain 3	2.99 (0.33)	69.5%
Domain 4	3.22 (0.39)	80%
Domain 5 (appraisal of health information)	2.88 (0.39)	57.5%
Domain 6	4.01 (0.46)	62%
Domain 7 (Navigating healthcare system)	3.84 (0.5)	52.5%
Domain 8 (ability to find good health info)	3.62 (0.55)	44%
Domain 9 (understanding info well enough to know what to do)	3.91 (0.51)	57%



#### **RSC patients**

+									
	90%	84%	67%	82%	70%	73%	60%	57%	75%
	1. Feeling understood	2. sufficient information	3. actively manage health	4. social support	5. appraisal of health info	6. actively engage	7. navigating system	8. find good health info	9. understand info to know what to do
	89%	72%	55%	72%	55%	78%	55%	55%	66%

RSC surrogate decision makers



- No significant different in HL domains with respect to age, gender, treatment of ESKD
- Linear regression analysis
  - having more than 3 co-morbidities and less than secondary education significantly association with reduced ability to find good health information and understanding health information well enough to know what to do



# Those who attended a RSC clinic found to have significantly better health literacy in domain 8

DOMAIN 8	LOW LEVEL OF CONSTRUCT	HIGH LEVEL OF CONSTRUCT
Ability to find good		
health information	Cannot access health	Is an "information explorer".
	information when required. Is	Actively uses a diverse range of
	dependent on others to offer	sources to find information and
	information.	is up to date.

Find information about health problems

Find health information from several different places

Get information about health so you are up to date with the best information

Get health information in words you understand

Get health information by yourself

	RSC-NFD	RSC-SS	HD	Home HD	PD
	N=17	N=21	N=38	N=16	N=17
1. Feeling	82%	95%	79%	94%	100%
understood	agreed or				
	strongly agreed				
2. Having sufficient	76%	90%	63%	75%	100%
information to	agreed or				
manage my health	strongly agreed				
3. Actively	66%	70%	53%	81%	94%
managing my	agreed or				
health	strongly agreed				
4. Social support	71%	90%	82%	69%	88%
for health	agreed or				
	strongly agreed				
5. Appraisal of	59%	76%	55%	50%	47%
health information	agreed or				
	strongly agreed				
6. Ability to	63%	81%	55%	69%	59%
actively engage	Usually or				
with healthcare	always	always	always	always	always
providers					
7. Navigating the	50%	67%	45%	50%	59%
healthcare system	Usually or				
	always	always	always	always	always
8. Ability to find	50%	62%	29%	50%	41%
good health	Usually or				
information	always	always	always	always	always
9. Understanding	50%	90%	42%	63%	65%
health information	Usually or				
well enough to	always	always	always	always	always
know what to do					

#### Table 5 Linkage between the Nutbeam [52] schema of health literacy and the Health Literacy Questionnaire (HLQ)

Nutbeam schema [52]	Broad matching HLQ domains*
i) Basic/functional health literacy: sufficient basic	9. Understanding health information well enough to know what to do
skills in reading and writing to be able function effectively in everyday situations.	2. Having sufficient information to manage my health
	8. Ability to find good quality health information
ii) Communicative/interactive health literacy: more advanced	Feeling understood and supported by healthcare providers
cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract	3. Actively managing my health
information and derive meaning from different forms of communication,	4. Social support for health
and to apply new information to changing circumstances.	6. Ability to actively engage with healthcare providers
	7. Navigating the health system
	8. Ability to find good quality health information
iii) Critical literacy: more advanced cognitive skills, which together	5. Appraisal of health information
with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events	3. Actively managing my health
and situations.	4. Social support for health

<sup>\*</sup> Within each HLQ scale there are some elements of the three levels of Nutbeam's schema so overlap is expected



#### 50% conservative patients felt they were able to adequately Understand health information well enough to know what to do

Conservative patients scored the lowest of all treatment modalities

ltem #	<b>High:</b> Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required
	<b>Low:</b> Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms
39	Confidently fill medical forms in the correct way
43	Accurately follow the instructions from healthcare providers
46	Read and understand written health information
51	Read and understand all the information on medication labels
55	Understand what healthcare providers are asking you to do



# 50% conservative patients felt they are able to adequately **Navigate the healthcare system**

Item #	<b>High:</b> Able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level.
	<b>Low:</b> Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.
35	Find the right health care
42	Get to see the healthcare providers I need to
45	Decide which healthcare provider you need to see
47	Make sure you find the right place to get the healthcare you need
50	Find out what healthcare services you are entitled to
53	Work out what the best care is for you



# 50% conservative patients felt they are able to adequately **Find good health information**

ltem #	<b>High:</b> Is an 'information explorer'. Actively uses a diverse range of sources to find information and is up to date.	
	Low: Cannot access health information when required. Is dependent on others to offer information.	
37	Find information about health problems	
40	Find health information from several different places	
44	Get information about health so you are up to date with the best information	
48	Get health information in words you understand	
52	Get health information by yourself	



#### What does this mean....

#### Our patients

- Become easily confused when given conflicting advice
- unable to advocate on their own behalf and don't know what is available to them
- Cannot find relevant information and rely on us to provide them with the right information
- Have problems understanding written information or instructions about their treatment

Their surrogate decision makers....may not be much better



### Translation into dietary education...

Studies have shown that knowledge does play a small but pivotal role in adopting dietary change

Barriers to dietary change are patients interpreting, translating and applying the nutrition messages

- we give people too much information
- health information is confusing (e.g. what is a serve of fruit?)
- confused by conflicting advice



#### How to reduce your salt intake

FOOD GROUP	SUITABLE	MINIMISE
FISH	Fresh fish Fish canned in spring water Canned salmon with no added salt	Smoked fish, Canned fish in brine or sauce eg herrings in tomato sauce.  Fish paste, Shellfish, prawns, shrimps, Ready made fish dishes.
MEAT & POULTRY	Fresh beef, minoe, lamb, pork, chicken, offal meats	Tinner - back meats Minoe Fruits and vegetables ar disease progresses, pot
MILK	Milk, all types, Cream, Butter, margarines (salt reduced types), Yoghurts, Cheese, (not more than 20g/ day), Cottage, edam and Gruyere cheeses are lower in salt	Chees chees You may be advised to li
EGGS	Eggs	Fruit and vegetables hig
VEGETABLES	Potatoes- baked, boiled, mashed, and roasted.  All vegetables (fresh and frozen)	Instan and d pure fruit juices labelle salt".  Baked Dehyd silverbeet, tomatoes
SOUPS	Home made soups using stock made from vegetables and meats and adding only a pinch of salt	Tinned Home powde Your doctor regularly che
SAUCES & PICKLES	Beetroot, home- made fresh salsas Worcester sauce (1tsp), Home made sawoury sauces. Tomato puree Prepared dried mustard. "Lite" bottled sauces, Mayonnaise	Stock Marmi Soya for help to choose suitable onions Packe
FRUIT	All fresh, tinned, dried, frozen	
DRINKS	Water Hot drinks including tea, coffee, cocoa and drinking chocolate Fruit juices, squashes and cordials Fizzy drinks	Stock broth Tomato juice Mineral waters and sports drinks

#### Vhat about fruit and vegetables?

Fruits and vegetables are important in your daily meals. They contain a mineral called potassium. As kidney lisease progresses, potassium in the blood may start to rise. This is because the kidneys are not able to emove extra potassium. This can be dangerous.

ou may be advised to limit or avoid certain types of fruits and vegetables that are high in potassium.

ruit and vegetables high in potassium include:

Your doctor regularly checks your blood potassium levels and will tell you if you need to cut down on high potassium fruits and vegetables in your diet. Your doctor can refer you to a dietitian for help to choose suitable fruits and vegetables.











## Improving our dietary interventions

Lambert, BMC nephrology, 2017 (systematic review)
Stevenson, Journal of Renal Nutrition, 2018 (qualitative interviews)

# Health care system factors that can help dietary adherence:

- advice from an experienced dietitian by providing practical, individualised, culturally relevant information
- encouragement to sustain dietary changes from all staff (i.e. nurses, nephs)
- ongoing education and support
- simplified nutrition messages utilising visual aids



## What could we be doing differently?

- Personalise information
- Test readability of our resources
- Use more visual aids
- Improve cultural sensitivity of our resources
- Improve actionability of our dietary resources

"consume less than 2300mg sodium / day"

→ "don't add salt at the table" / "choose foods with less than 400mg/100g on the food label"

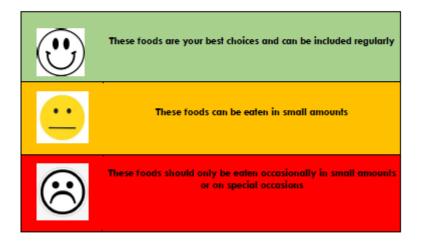


#### HEALTHY EATING FOR ADVANCED KIDNEY FAILURE

#### South Asian diets

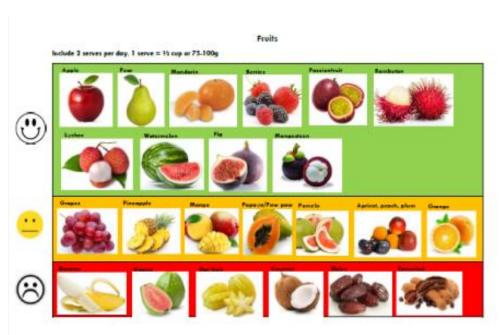
The following information has been developed for people with advanced kidney disease.

It will help you make choose foods and drinks that are lower in potassium, phosphorus and sodium.



This is general guidance.

You should speak with a distition who can provide you more individualised advice.



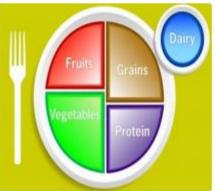


#### What can we do to feel as well as possible?

#### 1. Enjoy your food

- Important to balance the need of staying well, making good food choices and enjoying what you eat
- 2. Have regular meals during the day
- 3. Eat more fresh food instead of processed food
  - Fresh food will be lower in salt and phosphate which will help to put less pressure on the kidneys
  - Will help to reduce blood pressure, swelling in ankles, itchiness and general tiredness
- Boil vegetables instead of steaming, grilling, frying, roasting or baking
  - This will reduce the amount of potassium in the vegetables
- 5. Eating foods from a variety of food groups
  - Try to eat a variety of food from all the food groups rather than too much of one food/food group.







**Ith** n Eastern Sydney Health District

# Thank you

