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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)



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- 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.



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What is health literacy?

Health Literacy is:



your
health



health & health care
information



your health
decisions



making decisions
together



taking health
action



feeling good about
your health

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)	3 questions rated on scale of 1-5 <ul style="list-style-type: none"> - How confident are you filling out forms by yourself? - How often do you have someone help you read hospital materials? - How often do you have problems learning about your medical condition because of difficulty reading hospital materials? 	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



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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



		<i>Strongly disagree</i>	<i>Disagree</i>	<i>Agree</i>	<i>Strongly agree</i>
1	I feel I have good information about health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	I have at least one healthcare provider who knows me well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	I can get access to several people who understand and support me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	I compare health information from different sources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	When I feel ill, the people around me really understand what I am going through	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	I spend quite a lot of time actively managing my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	When I see new information about health, I check up on whether it is true or not	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



		<i>Cannot do or always difficult</i>	<i>Usually difficult</i>	<i>Sometimes difficult</i>	<i>Usually easy</i>	<i>Always easy</i>
1	Find the right health care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Make sure that healthcare providers understand your problems properly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Find information about health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Feel able to discuss your health concerns with a healthcare provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Confidently fill medical forms in the correct way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Find health information from several different places	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Have good discussions about your health with doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Get to see the healthcare providers you need to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Accurately follow instructions from healthcare providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.

5. Appraisal of health information (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	Haemodialysis	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



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

An average score of 3 or above was classified as adequate health literacy

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

An average score of 4 or above was classified as adequate health literacy



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	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



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-
- No significant difference 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 associated 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	<u><i>LOW LEVEL OF CONSTRUCT</i></u>	<u><i>HIGH LEVEL OF CONSTRUCT</i></u>
Ability to find good health information	<i>Cannot access health information when required. Is dependent on others to offer information.</i>	<i>Is an “information explorer”. Actively uses a diverse range of sources to find information and is up to date.</i>

- 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

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

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 skills in reading and writing to be able function effectively in everyday situations.	9. Understanding health information well enough to know what to do 2. Having sufficient information to manage my health 8. Ability to find good quality health information
ii) Communicative/interactive health literacy: more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances.	1. Feeling understood and supported by healthcare providers 3. Actively managing my health 4. Social support for health 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 with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events and situations.	5. Appraisal of health information 3. Actively managing my health 4. Social support for health

* 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

Item #	High: Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required	Low: 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 #	High: 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.
	Low: 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

Item #	High: 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



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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



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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, mince, lamb, pork, chicken, offal meats	Tinned – bacon, meats Mince Ready-made meat dishes
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	Cheese cheese
EGGS	Eggs	
VEGETABLES	Potatoes- baked, boiled, mashed, and roasted. All vegetables (fresh and frozen)	Instant and of label salt". Baked Dehydrated
SOUPS	Home made soups using stock made from vegetables and meats and adding only a pinch of salt	Tinned Home made powder
SAUCES & PICKLES	Beetroot, home- made fresh salsas Worcester sauce (1tsp), Home made savoury sauces. Tomato puree Prepared dried mustard. "Lite" bottled sauces, Mayonnaise	Stock Marmite Soya relishes onions Packets
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

What about fruit and vegetables?

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

You may be advised to limit or avoid certain types of fruits and vegetables that are high in [potassium](#).

Fruit and vegetables high in potassium include:

- bananas
- pure fruit juices
- dried fruit
- potatoes
- silverbeet, tomatoes

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.



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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



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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”*



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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.



























	These foods are your best choices and can be included regularly
	These foods can be eaten in small amounts
	These foods should only be eaten occasionally in small amounts or on special occasions

This is general guidance.

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

Fruits

Include 2 serves per day. 1 serve = 1/2 cup or 75-100g

Apple 	Pear 	Mandarin 	Berries 	Passionfruit 	Rambutan 		
	Lemon 	Watermelon 	Pine 	Mangosteen 			
	Grapes 	Pineapple 	Mango 	Papaya/Paw paw 	Peach 	Apricot, peach, plum 	Orange 
	Banana 	Guava 	Jackfruit 	Coconut 	Walnut 	Peanut 	

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

4. 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.



Thank you



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