Diet in the management of non-dialysis dependent Polycystic Kidney Disease (PKD):

Perceptions and experiences of people living with PKD

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Background

Renal Dietitians

- Nutrition interventions can help delay PKD progression
- Confusion on what to follow is common
- Access to renal dietitians limited
- Little is known about the patient experience before dialysis
- Opportunity to maximise eating behaviour change for better outcomes

Aim

Explore the views and experiences of patients living with non-dialysis dependent PKD on the role of diet in disease management

Method

A sequential-exploratory mixed methods approach

Online Survey

- 32 items (ethics approved)
- Questions: demographic, knowledge on nutrition and PKD and views on the role of nutrition in PKD progression

Recruitment

- Patient-advocacy kidney organisations
- PKD Facebook groups

Patient Interviews

- Semi-structured
- Questions: views on role of diet, information sources, experiences with dietary change, resources preferred

Recruitment

- From online survey – self nominated
- Application form via PKD Foundation

Over 1.5 years

Method

Survey Analysis:

- Tests based on distribution of data via SPSS

Regression modelling:

- Associations between:
  - referrals to dietitians
  - attendance
  - views on nutrition
  - other variables

Interview analysis:

- Inductive thematic analysis

Results

A total of 745 people completed the survey

and

A total of 10 people were interviewed

Survey Results

A total of 745 people completed the survey

Variable	n (%)	Variable	n (%)
Age			
18-29 years	30 (4)		
30-39 years	113 (15)		
40-49 years	129 (17)		
50-59 years	189 (25)		
60-69 years	193 (26)		
70 years and over	91 (12)		

Survey Results

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18-29 years	30 (4)		
30-39 years	113 (15)		
40-49 years	129 (17)		
50-59 years	189 (25)		
60-69 years	193 (26)		
70 years and over	91 (12)		
Gender			
Female	566 (76)		
Male	175 (23)		
Other	4 (1)		

Survey Results

A total of 745 people completed the survey

Variable	n (%)	Variable	n (%)
Age		**CKD Stage**	
18-29 years	30 (4)	Stage 1	176 (24)
30-39 years	113 (15)	Stage 2	127 (17)
40-49 years	129 (17)	Stage 3	206 (28)
50-59 years	189 (25)	Stage 4	118 (16)
60-69 years	193 (26)	Stage 5	38 (5)
70 and over	91 (12)	Unknown	72 (10)
Gender			
Male	566 (76)		
Female	175 (23)		
Other	4 (1)		

Survey Results

A total of 745 people completed the survey

Variable	n (%)	Variable	n (%)
Age		**CKD Stage**	
18-29 years	30 (4)	Stage 1	176 (24)
30-39 years	113 (15)	Stage 2	127 (17)
40-49 years	129 (17)	Stage 3	206 (28)
50-59 years	189 (25)	Stage 4	118 (16)
60-69 years	193 (26)	Stage 5	38 (5)
70 and over	91 (12)	Unknown	72 (10)
Gender		**Time since diagnosis**	
Male	566 (76)	Less than 5 years	102 (14)
Female	175 (23)	6-10 years	95 (13)
Other	4 (1)	11-15 years	91 (12)
		16 years and over	457 (61)

Survey Results

A total of 745 people completed the survey

Variable	n (%)	Variable	n (%)
Co-morbidities			
Diabetes	29 (4)		
Hypertension	555 (75)		
High cholesterol	158 (21)		
Heart disease	35 (5)		
Kidney stones	90 (12)		
Liver disease	80 (11)		

Survey Results

A total of 745 people completed the survey

Variable	n (%)	Variable	n (%)
Co-morbidities		**Location**	
Diabetes	29 (4)	USA	625 (84)
Hypertension	55 (75)	Australia	30 (4)
High cholesterol	158 (21)	Other	80 (12)
Heart disease	35 (5)		
Kidney stones	90 (12)		
Liver disease	80 (11)		

Survey Results

A total of 745 people completed the survey

Variable	n (%)	Variable	n (%)
Co-morbidities		**Location**	
Diabetes	29 (4)	USA	625 (84)
Hypertension	55 (75)	Australia	30 (4)
High cholesterol	158 (21)	Other	90 (12)
Heart disease	35 (5)	**Education level**	
Kidney stones	90 (12)	High school	56 (7)
Liver disease	80 (11)	Community college/TAFE	110 (15)
		University	576 (77)
		Other	3 (1)

Referral patterns and patient perspective on diet

Variable	n (%)
Importance of diet in PKD	
Slight	9 (1)
Moderate	76 (11)
Very – extremely	596 (88)

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Not advised to see dietitian	536 (72)

Referral patterns and patient perspective on diet

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Importance of diet in PKD	
Slight	9 (1)
Moderate	76 (11)
Very – extremely	596 (88)
Not advised to see dietitian	536 (72)
Was not advised but interested in seeing a dietitian	352 (52)

Referral patterns and patient perspective on diet

Variable	n (%)
Importance of diet in PKD	
Slight	9 (1)
Moderate	76 (11)
Very – extremely	596 (88)
Not advised to see dietitian	536 (72)
Was not advised but interested in seeing a dietitian	352 (52)
Saw dietitian	278 (38)
Renal dietitian	113 (44)
General dietitian	112 (44)
Didn't know	29 (11)

Factors influencing patient interest in a referral to dietitian

Variable	Odds Ratio	95% CI	P-value
Location – USA*	0.33	0.16 – 0.71	0.004
Education – community college or TAFE**	2.31	1.13 – 4.73	0.021
CKD function (Stages 1-2)***	3.56	1.57 – 8.09	0.002
Time since diagnosis (0-5 years) ****	1.94	1.01 – 3.74	0.048

*Rest of the world is the reference category
**High school education is the reference category
***Unknown CKD function is reference category
****Time to diagnosis of >16 years is the reference category

Factors influencing referrals made to dietitians

Variable	Odds Ratio	95% CI	P-value
CKD function - Stage 3*	2	1.28 – 3.15	0.03
CKD function – Stage 4*	2.73	1.62 - 4.57	<0.001
CKD function – Stage 5*	7.14	3.17 - 16.08	<0.001
CKD function – unknown*	2.47	1.32 - 4.63	0.005
Gender – Male**	1.57	1.04 - 2.38	0.031

*CKD Stages 1-2 is the reference category
**Female gender is the reference category

Factors influencing patient attendance to dietitian appointments

Variable	Odds Ratio	95% CI	P-value
Education – University*	2.02	1.25-3.28	0.004
Patient perceived importance of diet**	1.7	1.01-2.87	0.046

*High school education is the reference category
**Lower patient perceived of importance is the reference category

Non-dietetics nutrition advice provided

Variable	n (%)
Advice from nephrologists	
Low salt	530 (78)
Low protein	256 (38)
Low potassium	142 (21)
None	102 (15)
Advice from GPs	
Low salt	268 (39)
Low protein	71 (10)
Low potassium	32 (5)
None	370 (54)

Patient perspective on diets

Variable	n (%)
Most helpful	
Low salt	615 (90)
Low protein	449 (66)
Vegan/vegetarian	394 (54)
Low fat	171 (25)
Low carbohydrate/keto	161 (24)
Motivation to change if they knew it will help reduce PKD progression	
Very - extreme	633 (91)

Patient challenges and preferred support

Variable	n (%)
Challenges	
Hard to follow	126 (19)
Hard to put together	222 (33)
Hard to eat out	240 (35)
Support preferred	
Better nutrition resources	485 (71)
Access to renal dietitian	249 (37)
Kidney support groups	215 (32)

Patients who saw a renal dietitian were significantly more satisfied with the consultation(s) compared to those who saw a general dietitian (73% vs 46%; p-value <0.001)

Patient preferences for nutrition advice delivery

Variable	n (%)
Online	360 (53)
In-person	239 (35)
In-person group	82 (12)

Patient interview results

Variable	n (%)
Age*	50 (10.5)
Gender (Female)	5 (50%)
Years since diagnosis*	17 (13.3)
eGFR*	43 (11.4)
Education (Tertiary)	9 (90%)
Location (USA)	9 (90%)
Seen dietitian	6 (60%)

*Data represented as mean (standard deviation)

Themes

1

Patients' perceptions not matched to nephrologists

- Ambivalence to impact of nutrition
- Discounted impact of nutrition changes
- Affected motivation for change

"The idea of diet being a main thing that, you know, I'm just super frustrated that doctors are not more willing to either give that a chance. I mean, every time I've talked about different dietary things, I mean, the doctors are kind of like, do whatever you want, I don't think it's going to matter."

2

Patients' main source of nutrition information was self-research

- Uncertain what will work
- Willing to try alternative diets

"I mean, it forces, you, you know, to look for other options. And just kind of, like doing my own research, and my doctor is not willing to say one way or the other. Like, I'm gonna go look and see what has worked for other people."

Themes

3

Dietary change is a hard process

- Feeling restricted
- Cooking skills need to be optimal
- Eating out and socialising is a different experience now

I think the hardest was just figuring out how to manage all."

4

Routine support from renal dietitians is desired

- Must be personalised
- Want practical advice on how to change
- Disappointed with general CKD advice

"If there was like a nutrition component from like the first get go. And it was every visit to the doctor, I met with the nutritionist."

- Selection or respondent bias
- Location
- Impacts generalisability

Conclusion

- In this study, patients are **not** routinely referred to renal dietitians until later stages of PKD
- Yet perceive diet as a **very important part** of PKD management
- Evidence-based nutrition interventions for this population are desired from diagnosis
- **Changing current models of care and referral practices** for earlier access to renal dietitians is recommended
- RCT recommended to investigate impact on progression