Understanding drivers of decisional delay in CKD to optimize care and education

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THE CKD context

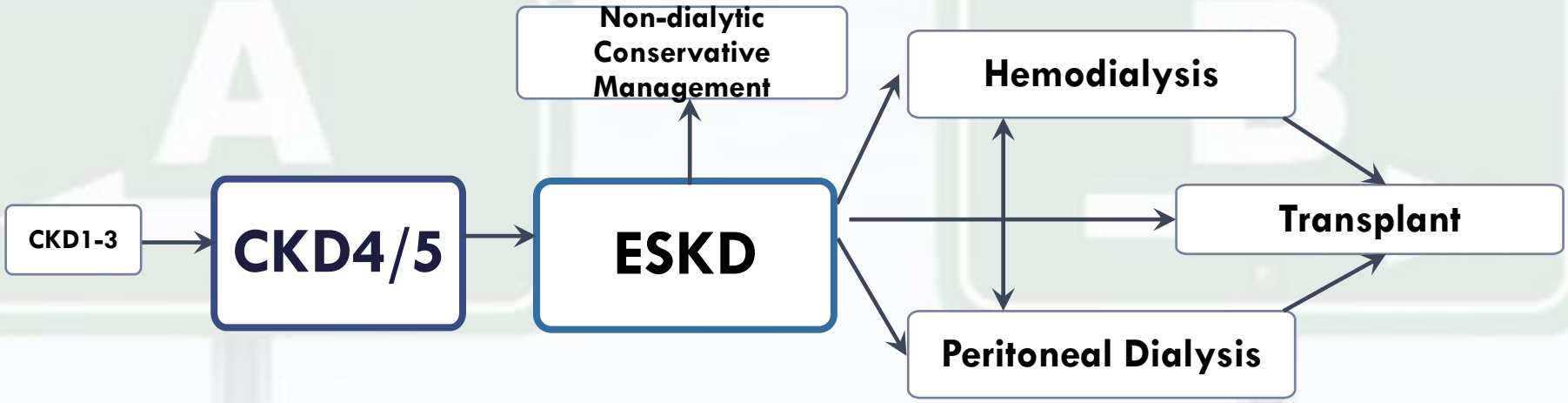
- CKD in top NCDs necessitating global health action (UN WHO, 2011)
  - 1 in 4 Singaporeans projected to develop CKD by 2035 (Wong, Toh & Tham, 2017; Wong et al., 2018)

- Increasing numbers due to diabetes and ageing
  - **More complex health care** needs and regimens
  - **New challenges for renal care services**

- Significant impact on individual, family, system(s)

- Increased Demands on **health care resources**
  - Efforts to increase home dialysis

FOCUS ON CKD



- High rates of suboptimal initiation onto RRT (unplanned initiation with no permanent access in place) –
  - USRD 2018. 36% of ESRD received little to no nephology care
  - Decision delay and unplanned start even when pts known to renal care (57% UK; 44% SG)
- High risk for infections and mortality; high health care costs
- Current CKD pathways need to be optimized
  - Pre-dialysis education

Perspectives Matter

What we (tend to) see …

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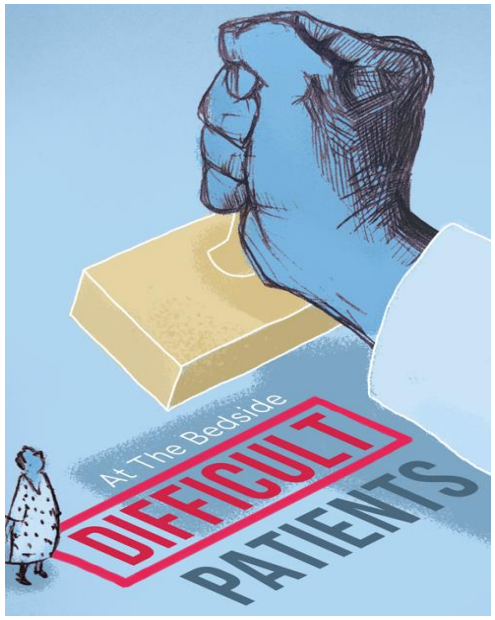


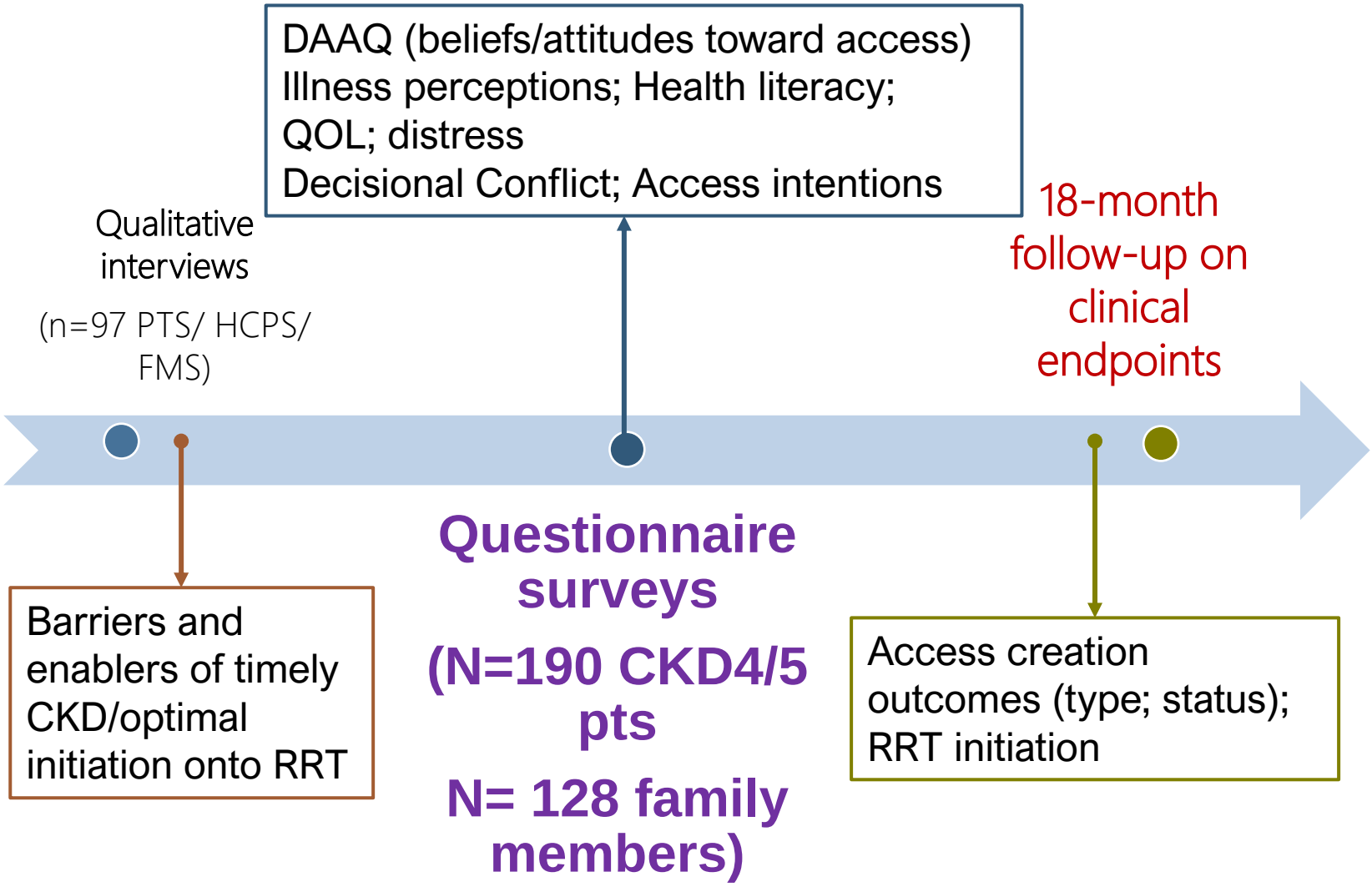
What's more or what else is there?

Study Aims

- To document rates of decisional delay and access outcomes in CKD patients **known to renal care**
- To develop a tool to measure patients' attitudes
- To identify (modifiable) factors associated with delay and suboptimal initiation onto dialysis
- **Support the optimization of renal services and patient education**

Methodology

Mixed methods prospective study



Griva et al 2020; Chia, Goh..Griva, 2021

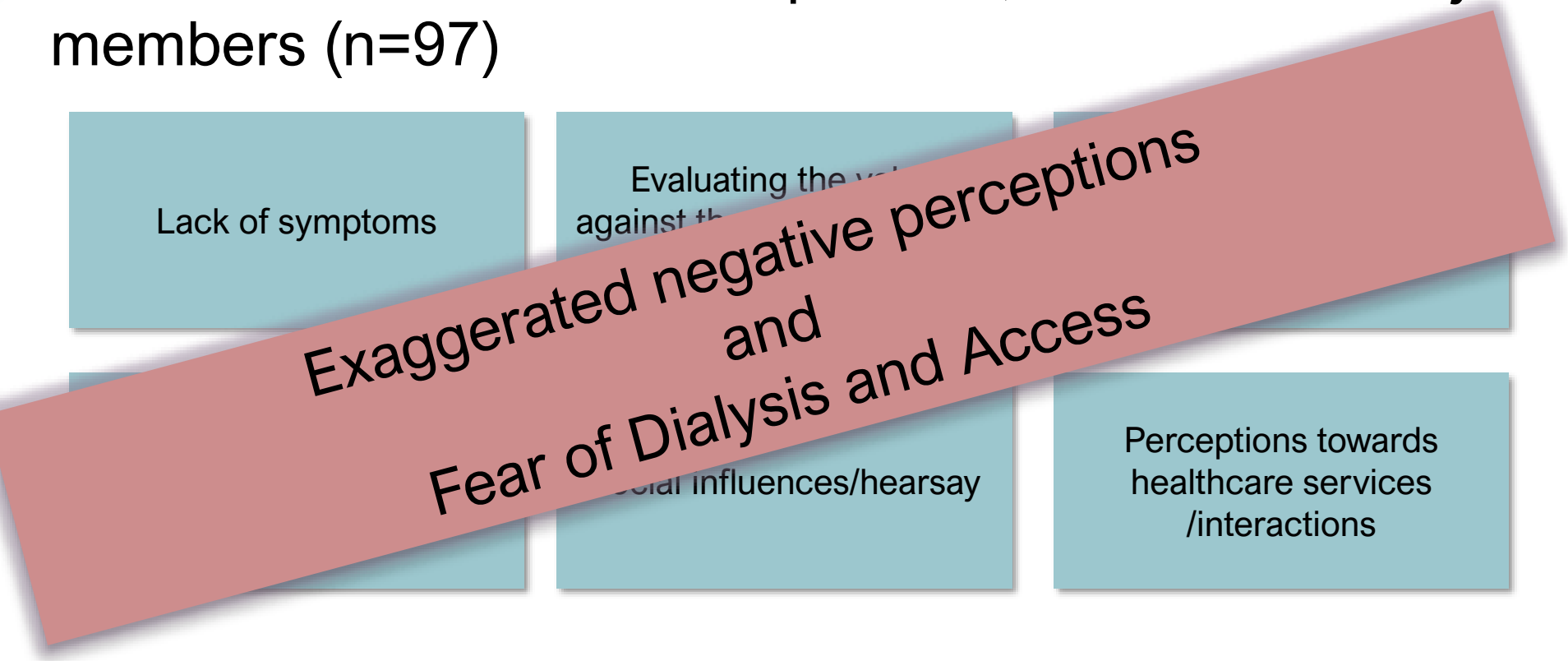
Results

Qualitative Study – Sample (N=97)

	Overall	Pre-dialysis patients	Dialysis pts with AVF	Dialysis pts without AVF	FAMILY	HCPS
	97	**31**	**18**	**20**	**19**	**9**
Mean Age (SD)	59.29 ± 12.27)	66.20 ± 10.58	61.00 ± 9.15	59.05 ± 7.72	56.88 ± 11.45	37.89 ± 7.04
Gender						
Male	52 (54%)	21 (68%)	12 (67%)	11 (55%)	4 (21%)	4 (44%)
Ethnicity						
Chinese	68 (70%)	22 (71%)	13 (72%)	13 (65%)	14 (74%)	6 (67%)
Malay	22 (23%)	7 (23%)	4 (22%)	4 (29%)	5 (26%)	2 (22%)
Others	7 (7)%	2 (6%)	1 (6%)	3 (15%)	0	1 (11%)
Relationship status						
Married	44 (67%)	18 (64%)	12 (66%)	14 (70%)		
Divorced/Widowed	11 (17%)	5 (18%)	2 (12%)	4 (20%)		
Single/ Living with partner	11 (16%)	5 (18%)	4 (22%)	2 (10%)		
Months since referral to RC	20.8 ± 19.1	26.2 ± 24.4	20.3 ± 13.3	13.0 ± 10.5		
eGFR (mL/min)		11 ± 4.51				
Causes of ESRD						
DM		17 (55%)	13 (72%)	9 (45%)		
Others		9 (29%)	5 (28%)	5 (35%)		

Bringing LIFE into “DIElysis”

Interviews with CKD/ESKD patients, HCPs and family members (n=97)



Griva, et al. (2020); Kidney Med

Unspoken barriers…

Fear of Dialysis (40.6%)

D09: I thinking dialysis will be the **end of the day will be a dead end**

C11: Dialysis no cure, dialysis just **waiting for die only.**

C22: Ya lah, just to prolong my agony that's all, nothing else right? **Matter of time I die**.

Unspoken barriers …..

Fistula Concerns (29.8%)

Fear of Surgery

C17: I / don't want **to cut** means I don't want to cut. I understand the procedure. I just don't want to go operate. Nobody wants to go operation. **They cut here cut there**

Fistula Viability

A14: I made my preparation early but my preparation (fistula) is spoilt. Then how, if do a another spare one, no don't want.

Fistula misconceptions

D07: Because **I thought when you do this fistula already then you have to do dialysis already**

Low awareness of benefits

Dialysis Access Attitudes Questionnaire (DAAQ)

Access and Dialysis Concerns

- Having to undergo the operation for dialysis access (fistula/PD catheter) worries me
- I worry about the effects of having the fistula/ PD catheter on my everyday life.
- I am worried that the fistula will fail to work
- I will worry about having to start dialysis earlier than usual once the fistula is in place
- I am afraid of dialysis because of the bad things people say about dialysis

Value of Access

- I see several advantages/benefits of preparing the fistula early
- Early fistula creation will make transition to dialysis more smooth in the future

Need for Dialysis

- I do not see any value in early fistula creation as I may never need dialysis
- I do not need dialysis as I feel that I am fine (no or minimum symptoms)
- My symptoms are not due to my kidney condition

Worry about Cost

- I am concerned about the cost of the fistula/ PD catheter surgery
- I worry about the cost of dialysis

Chia, Goh,.. Griva (2021) , Am J Kidney Disease

Measures

- Functional, Communicative, and Critical Health Literacy Questionnaire (FCCHL)
- Health Literacy Questionnaire (HLQ)

- Brief Illness Perception Questionnaire (BIPQ)
- Hospital Anxiety and Depression Scale (HADS)
- Kidney Disease Quality of Life – Short Form (KDQOL-SF)

- Ottawa Personal Decision Guide

- Sociodemographic, clinical info
  e.g. age, ethnicity, employment, eGFR , laboratory biochemical markers

- Intention related to access : proceed vs. wait and see
- Decisional Conflict Scale (DCS)
- ACCESS creation outcomes (18 months)

Study Sample (Patients)

No. of participants

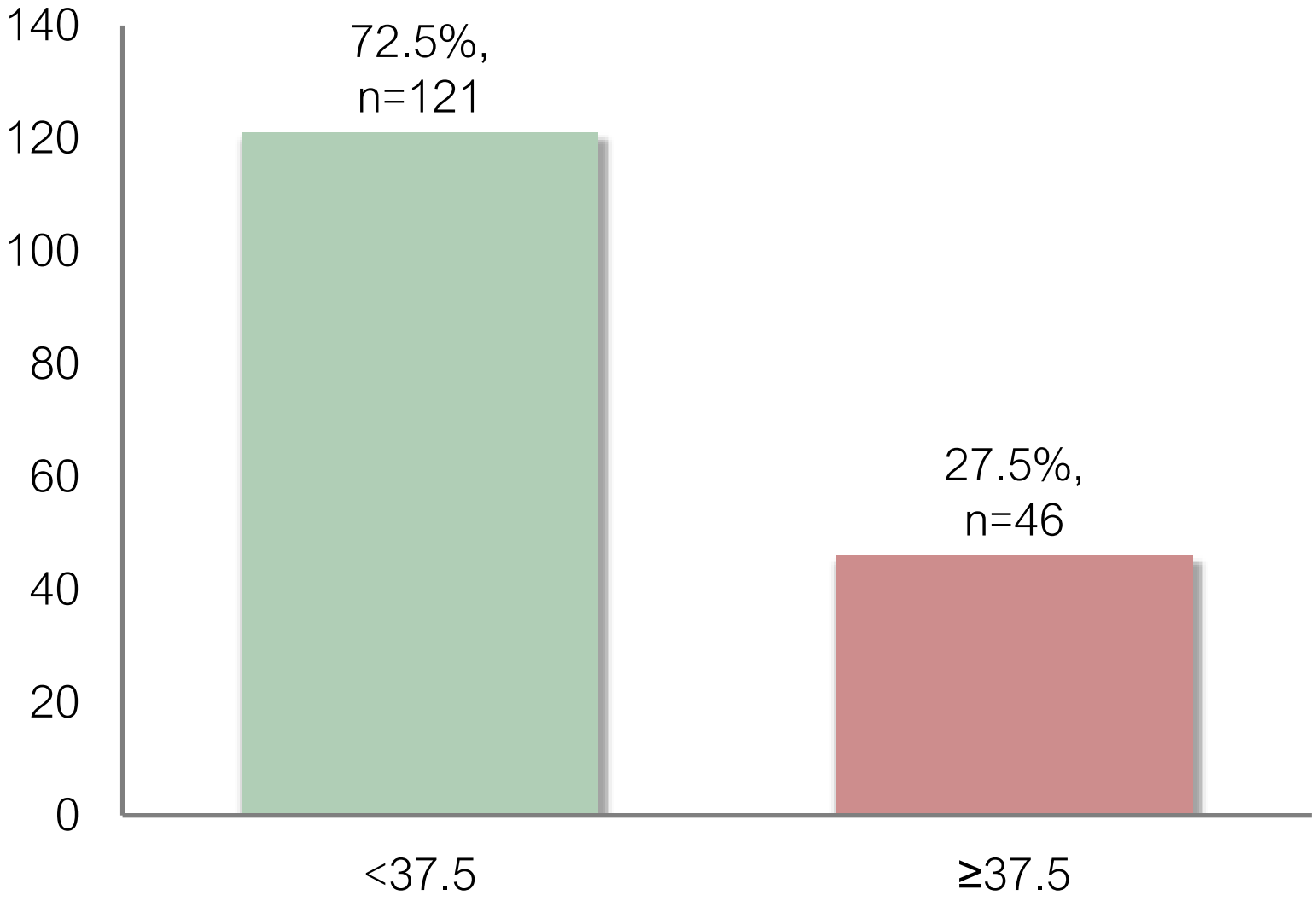
N=190

	Male, n=112	Female, n=78
	M ± SD	N (%)
Age	62.82 ± 10.83	
Marital Status (Married)		135 (71.4)
Ethnicity		
Chinese		114 (60.0)
Malay		53 (27.9)
Other Ethnicities		23 (12.1)
Education level		
Primary Education or lower		83 (45.1)
Secondary Education		60 (32.6)
Post Secondary		27 (14.7)
Tertiary and above		14 (7.6)
Employment status (Employed)		72 (37.9)
Household income		
<S$2000		73 (39.2)
S$2000-4999		41 (22.0)
S$5000-9999		21 (11.3)
S$10,000-17,999		13 (7.0)
>S$18,000		4 (2.2)
Don't know/ Don't wish to answer		34 (18.3)

Study Sample (Patients)

	Mean ± SD
Biomedical markers	
CKD-EPI eGFR (ml/min/1.72m^2)	10.46 ± 4.69
Urea (mmol/L)	22.87 ± 6.65
Potassium (mmol/L)	4.74 ± 0.59
Bicarbonate (mmol/L)	21.25 ± 3.13
Creatinine (umol/L)	501.23 ± 205.99
Albumin (G/L)	37.21 ± 5.29
Calcium, serum (mmol/L)	2.16 ± 0.19
Phosphate Inorganic (mmol/L)	1.61 ± 0.38
HbA1c (%)	7.05 ± 1.56
Haemoglobin (g/dL)	10.00 ± 1.44
Cause of ESKD N (%)	
Diabetes Mellitus	118 (68.2%)
Hypertension	24 (13.9%)
Chronic Glomerular Nephritis	16 (9.2%)
IgA Nephropathy	3 (1.7%)
Others	12 (6.9%)
Comorbidities	
Diabetes Mellitus	127 (66.8%)
Hypertension	162 (85.3%)
Days since RRT Counselling	126.16 ± 108.84

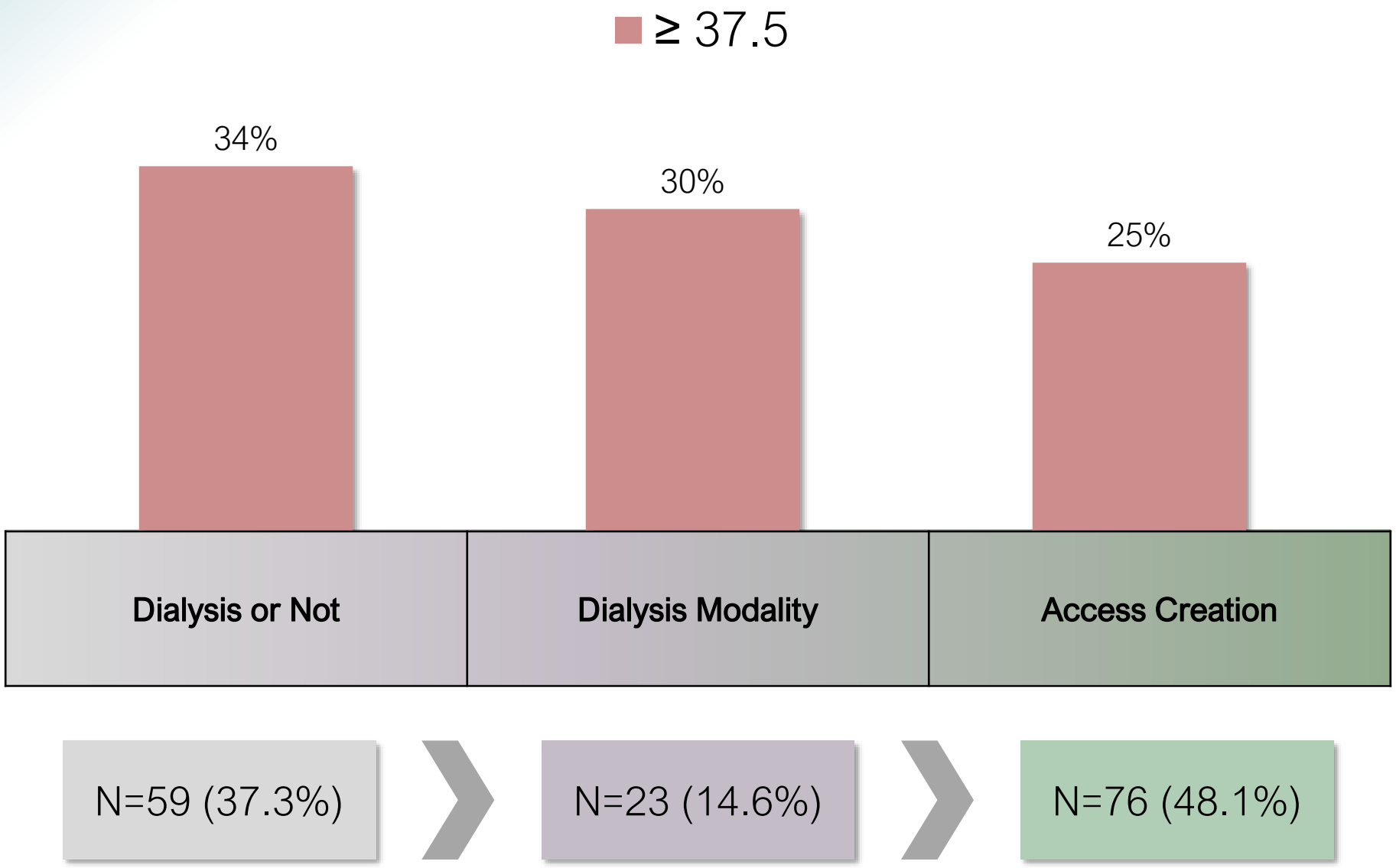
DCS
Clinically Significant Decisional Delay



Decision juncture and delay

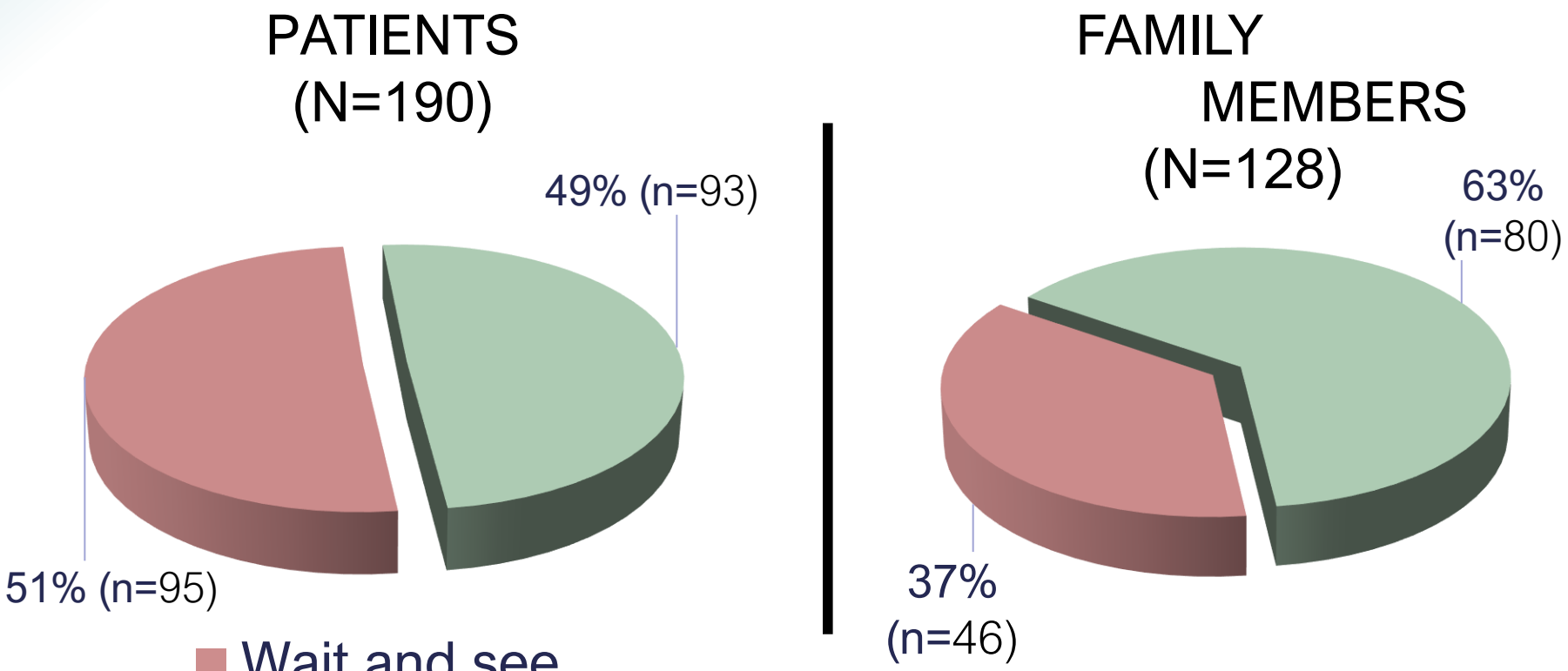
Dialysis or Not	Which Modality	Access Creation
I am deciding whether or not to go for dialysis	I am deciding between going for hemodialysis or peritoneal dialysis	I have decided for which dialysis to go for. I am now deciding when I should go for the dialysis access creation
N=59 (37.3%)	N=23 (14.6%)	N=76 (48.1%)

Decisional delay/conflict - Patients



Goh., Z. S., Chia, J. M. X., …, Griva., K. (in press). Treatment-related Decisional Conflict in Pre-Dialysis Chronic Kidney Disease Patients: Prevalence and Determinants. British J Health Psychology.

Intention to prepare dialysis access



*Significantly more FMs report intention to create access (χ^2=6.0, p=014)

Access Intentions

- 51.1% participants delay intention/ "wait and see in creating AVF"

Multivariable model	Significant predictors
Intention to proceed with access	• eGFR (OR=0.84) • Perceived value of access (OR=2.61) • Emotional representation (OR=1.18) • Patient satisfaction (OR=1.03) • General health (OR=0.96)

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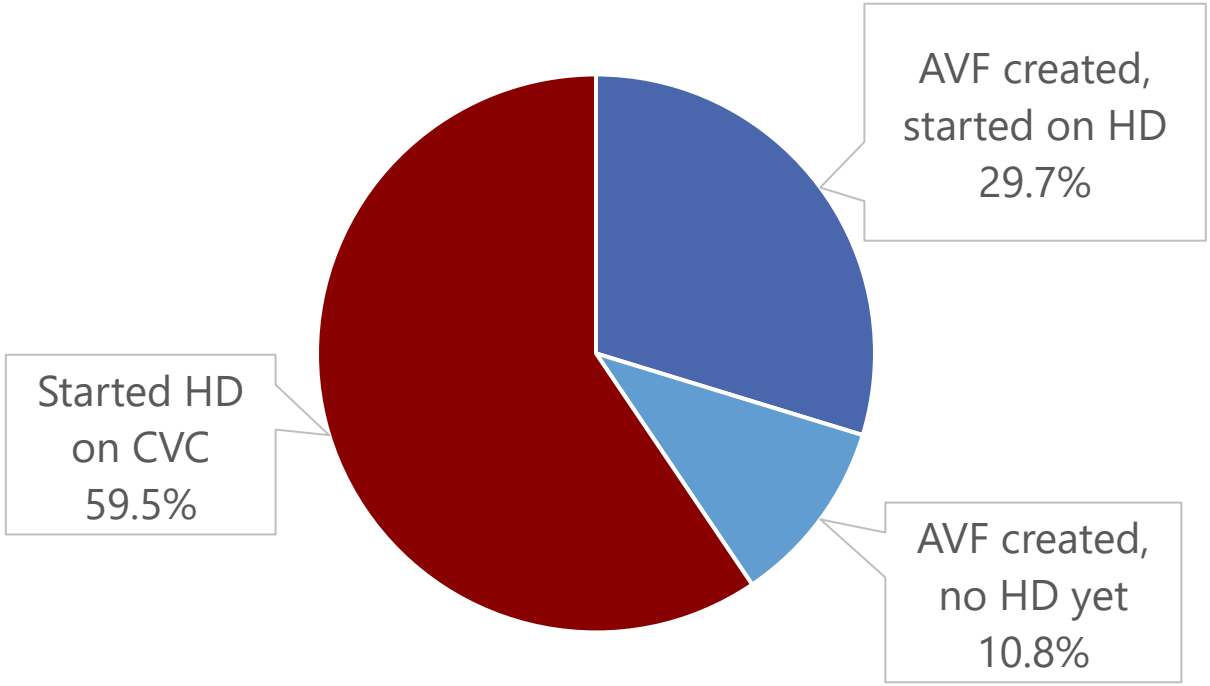
Access creation outcomes at 18 months

- 40.5% with functioning access in place



Censored: pending (n=12), lost to follow up/died/conservative (n=23), planning for/started on PD (n=44)

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Access creation outcomes at 18 months

- 40.5% with functioning access in place

Multivariable model	Significant predictors
Access creation outcome	• Age (OR=1.04) • eGFR (OR=0.87) • Perceived value of access (OR=1.60) • Illness consequences (OR=1.25) • Physical component summary (OR=0.96) • Effects of kidney disease (OR=0.98)

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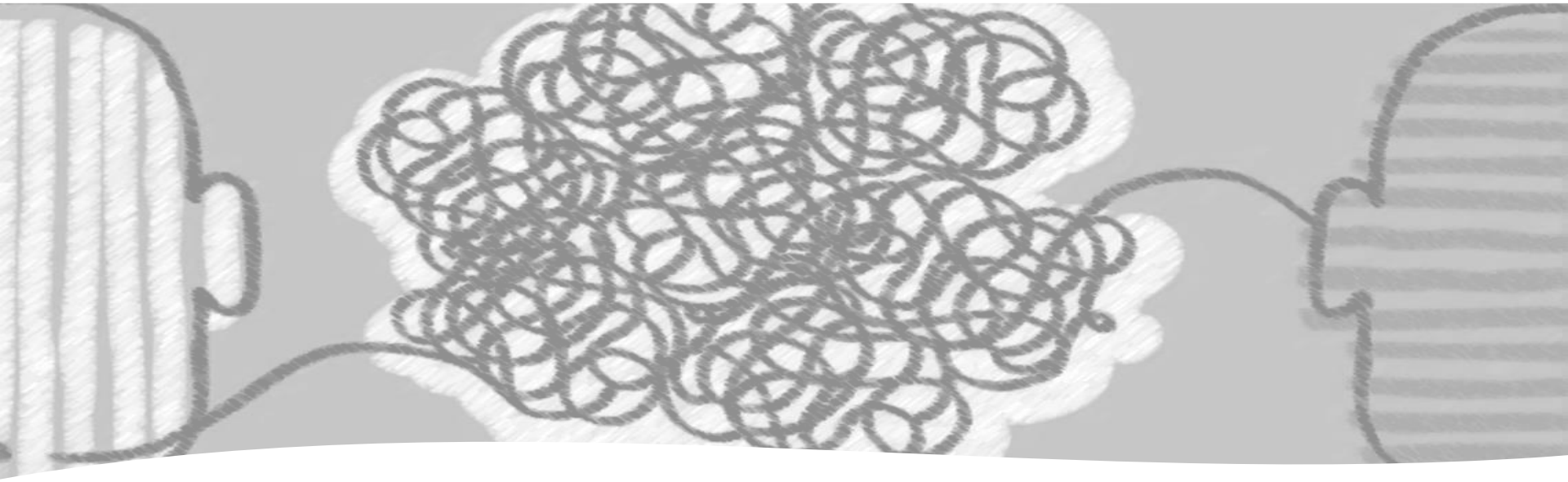
Discussion



- Clinically significant decisional delay and insistently high rates of delay intention and suboptimal initiation onto HD despite RRT counselling

- Patient beliefs are critical - need to better align content of predialysis educaion
  - Unspoken fears and misperceptions
  - "Value of access" – explore / reinforce
  - DAAQ – tool to elicit concerns and guide education/conversations

Thank you

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