



# Family functioning in people with medically refractory epilepsy

**A/Prof Sarah Wilson**

Melbourne School of Psychological Sciences,  
The University of Melbourne

Comprehensive Epilepsy Program,  
Austin Health, Melbourne



## Psychosocial difficulties for all family members

- ↓ social activities, stigmatization, ↓ self-esteem, psychiatric morbidity, marital problems
- interactions (e.g. overprotectiveness) in the family are key to family adjustment

Limited research: which epilepsy factors are important?

no epilepsy-specific measures of family functioning





THE UNIVERSITY OF  
MELBOURNE

New interactive computer software

# Living with Epilepsy

Experiencing epilepsy and its treatment



THE UNIVERSITY OF  
MELBOURNE





# Living with Epilepsy

Experiencing epilepsy and its treatment

This program is about 'Living with Epilepsy'.

We are interested in your views.

Thank you for taking part in our study.

This program is about how you see yourself and your life,  
and what living with epilepsy and its treatment means for you.

There are no right or wrong answers to any of these questions.

We are interested in your views.

Your thoughts about living with epilepsy  
will help us understand the challenges and  
opportunities faced by people before and after surgery.

We believe this information will help improve  
the healthcare we can provide.





## My Life at Present

People in my life in my family

Add a family member



### My Family



Press the arrow when you're ready





## My Life and My Epilepsy

My family's support for me with my epilepsy

My family members



Press the arrow button  
when you are happy  
with your positioning.





## My Life and My Epilepsy

My family's support for me with my epilepsy

### My family members



Mary

To me  
Mary  
is:

**3** **Totally supportive**

**2** **A good bit supportive**

**1** **A little bit supportive**

**0** **Not at all supportive**

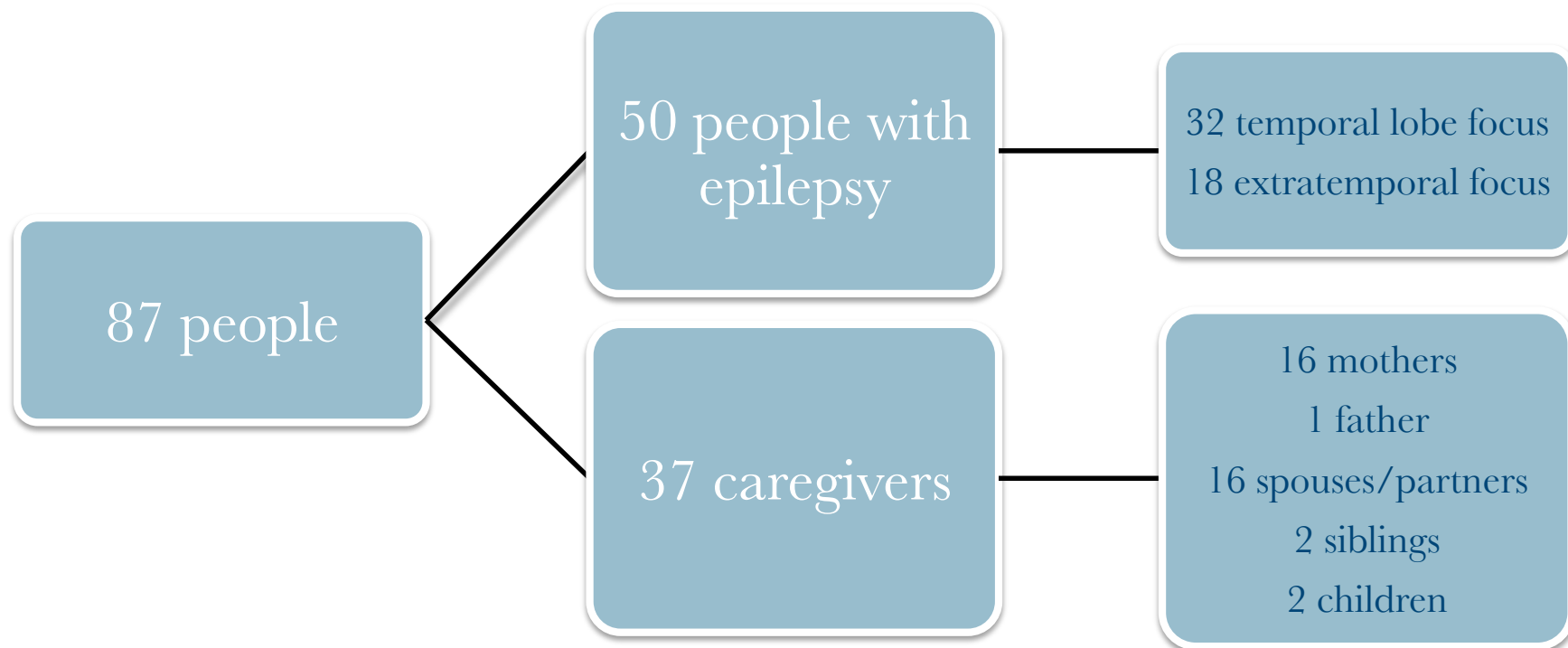
Press the arrow when you're ready





People with medically refractory focal epilepsy

- consecutively recruited through the CEP at Austin Health







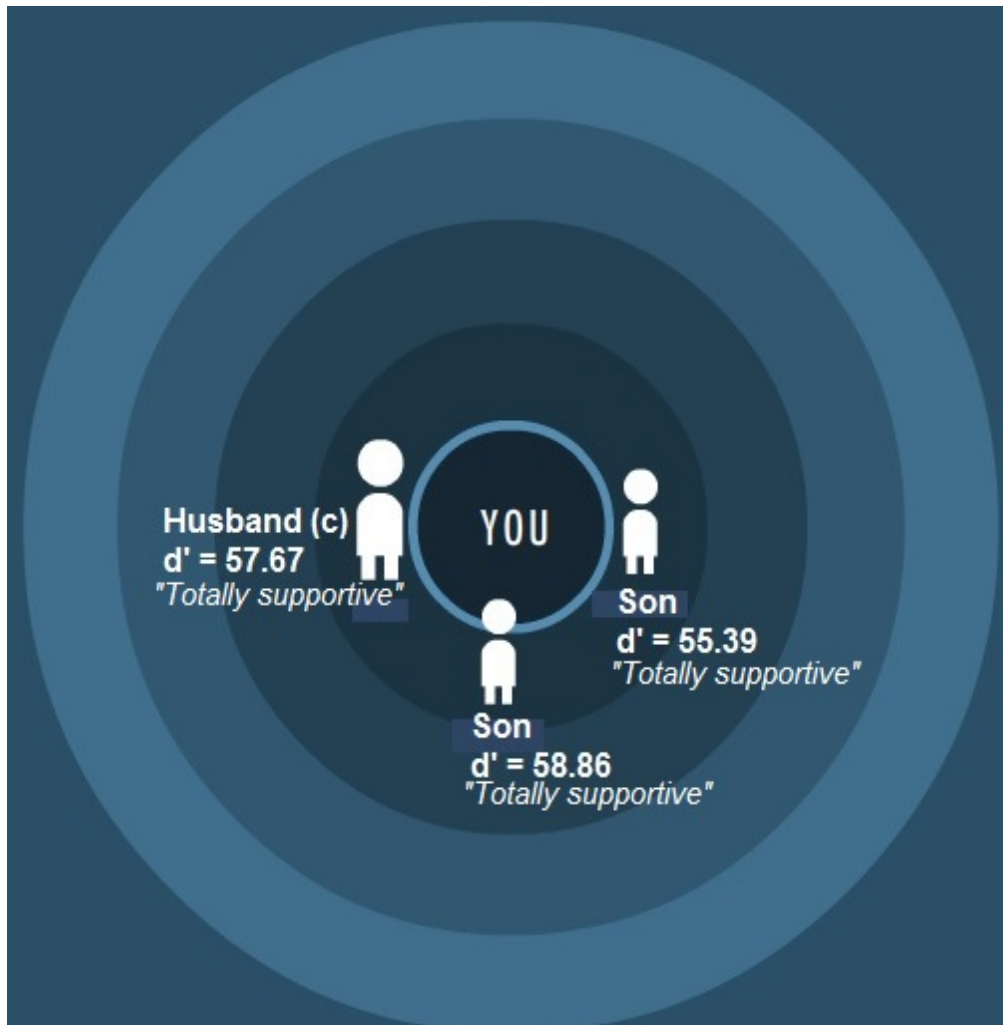
## Who participated?

	People with epilepsy (n=50)	Caregivers (n=37)
Gender (n, %) - female	28 (56%)	28 (76%)
Mean age (yrs, SD)	37 (12)	49 (15)**
Mean education (yrs, SD)	14 (3)	13 (3)
Employment (n, %) - employed	25 (50%)	26 (70%)*
Marital status (n, %) - partner	31 (62%)	29 (78%)
Living arrangements - parents	17 (34%)	2 (5%)*
- partner	26 (52%)	28 (76%)
- shared	4 (8%)	3 (8%)
- alone	3 (6%)	4 (11%)

\* $p < 0.05$ ; \*\* $p < 0.001$



## Type 1: 'Well adjusted'



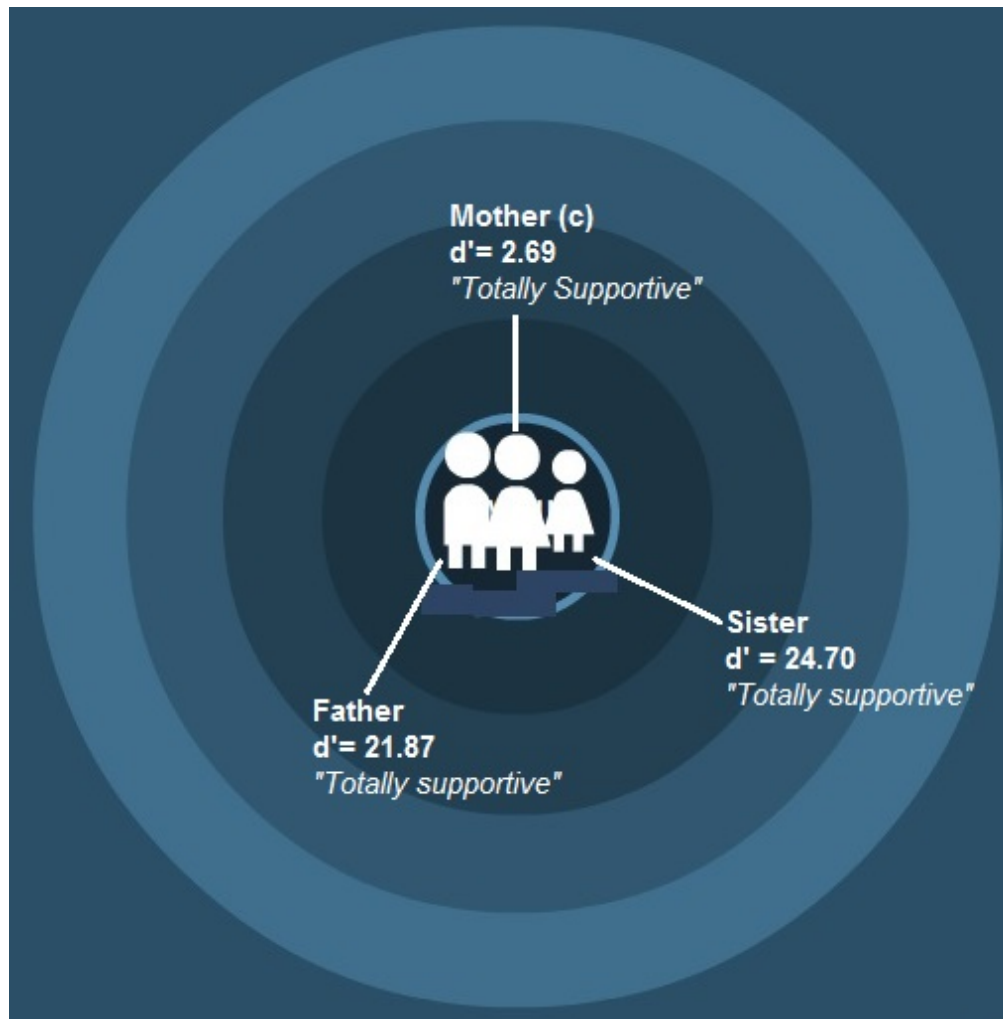
Shown by the majority:

- 20 patients (43%)
- 19 caregivers (56%)

For patients showing well adjusted families, 56% of caregivers agreed



## Type 2: 'Enmeshed'



Shown by ~one third:

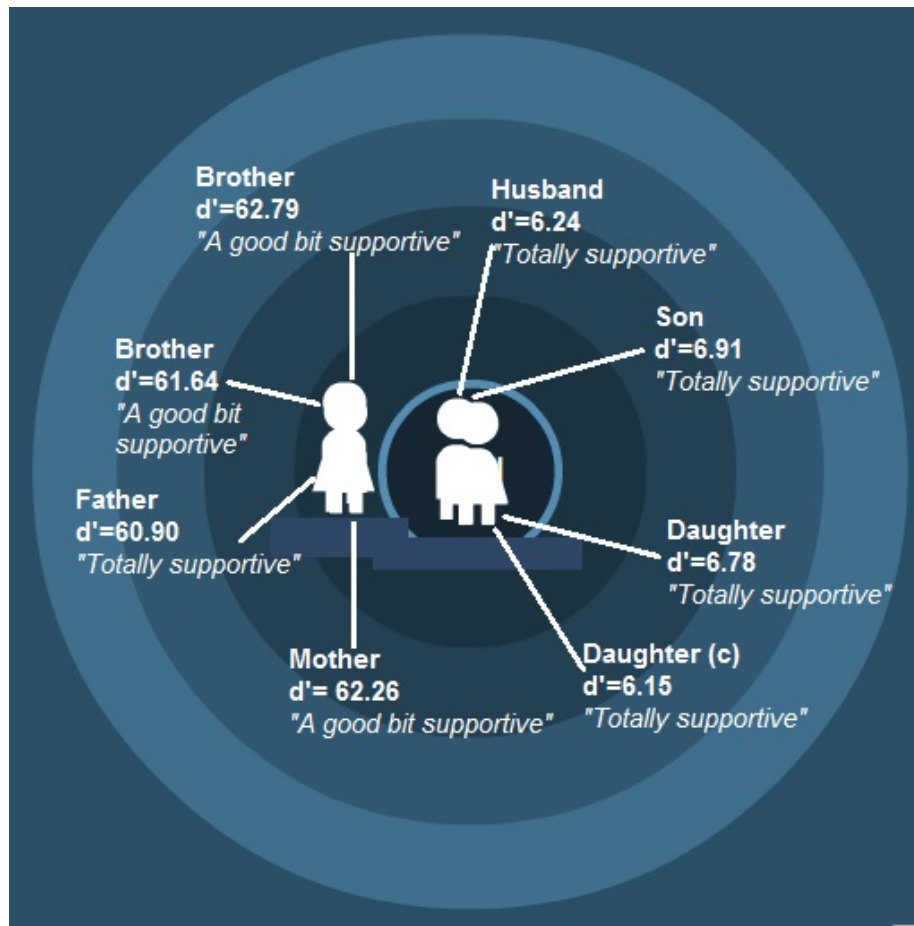
- 16 patients (34%)
- 10 caregivers (29%)

For patients showing enmeshed families, 45% of caregivers agreed

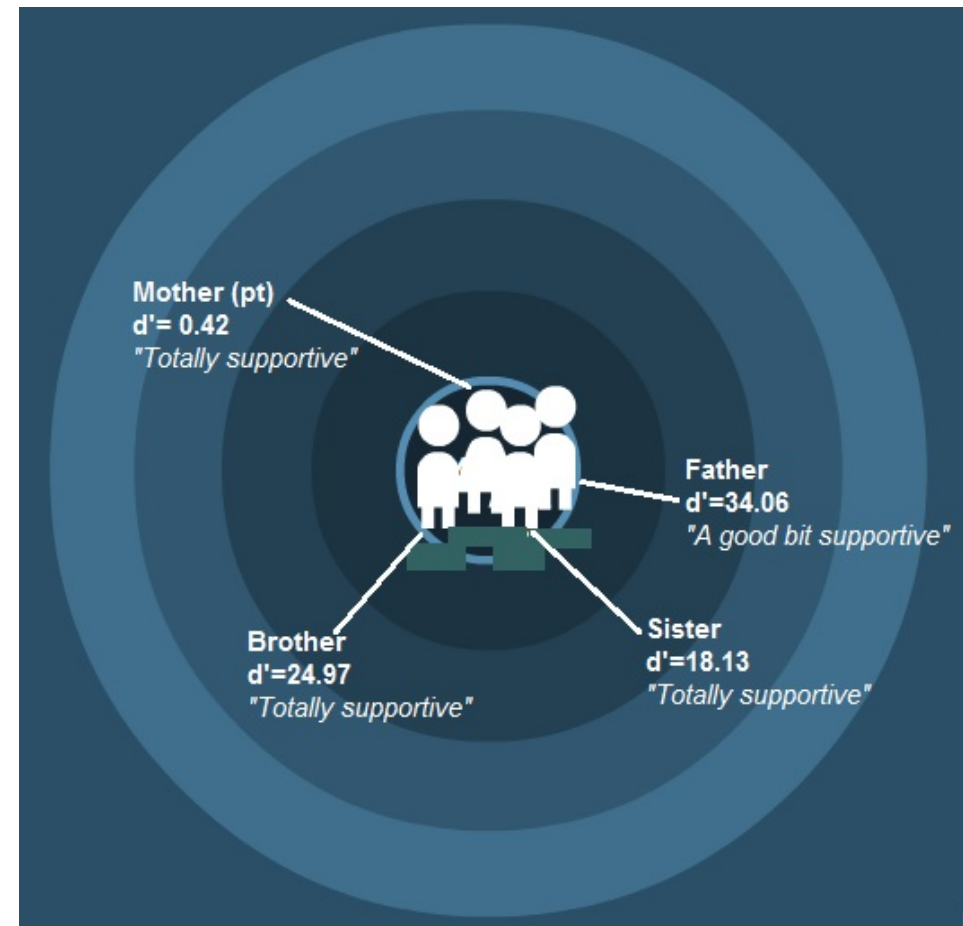
- most caregivers (86%) who didn't agree showed their family as well adjusted



## Concordant 'enmeshed' family maps



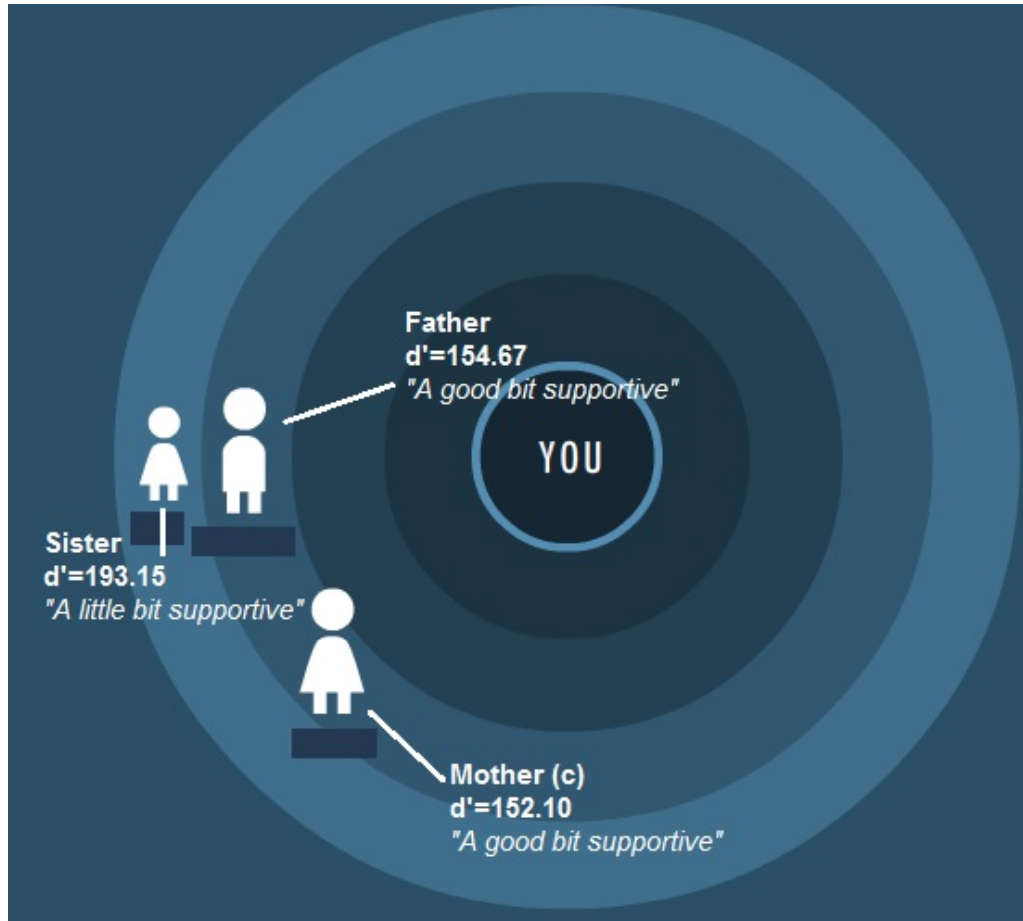
*Example of mother's map (patient)*



*Example of adult daughter's map (caregiver)*



## Type 3: 'Fractured'



*Example of patient map*

Shown by the minority:

- 11 patients (23%)
- 5 caregivers (15%)

For patients showing fractured families, 25% of caregivers agreed

- most caregivers (50%) who didn't agree showed their family as well adjusted (all mothers)



## Family Adaptability and Cohesion Evaluation Scales (FACES IV)

	'Well adjusted' (n=20)	'Enmeshed' (n=16)	'Fractured' (n=11)
Family map: Average closeness	77.7	41.8**	93.9
'Balanced Cohesion' (mean %, SD) - range	65 (16) 20 - 85	64 (18) 24 - 85	46 (15)* 30 - 82
'Balanced Flexibility' (mean %, SD) - range	46 (15) 20 - 80	39 (14) 16 - 62	34 (7)* 26 - 50
'Unbalanced Disengaged' (mean %, SD) - range	20 (7) 12 - 34	20 (10) 10 - 36	34 (16)** 12 - 60
'Family Communication' (mean %, SD) - range	64 (25) 28 - 99	58 (29) 10 - 97	31 (31)* 10 - 90
'Family Satisfaction' (mean %, SD) - range	59 (26) 10 - 98	54 (30) 10 - 99	37 (31) <sup>tr</sup> 10 - 87

\* $p \leq 0.05$ ; \*\* $p < 0.01$

Provides good convergent validity for the interactive computer software



For patient family maps:

	'Well adjusted' (n=20)	'Enmeshed' (n=16)	'Fractured' (n=11)
Mean age of epilepsy onset (yrs, SD) - range	24 (14) 8 - 63	19 (13) 1.5 - 47	14 (11)* 2 - 37
Mean duration of epilepsy (yrs, SD) - range	16 (10) 3 - 41	16 (13) 2 - 38	18 (13) 2 - 39
Mean seizure frequency (monthly, SD) - range	34 (89) 1 - 400	32 (52) 1 - 200	19 (27) 1 - 90
Mean age (yrs, SD) - range	39 (12) 24 - 67	35 (11) 23 - 57	33 (10) 20 - 49
Mean FSIQ (SD) - range	103 (13) 74 - 125	96 (12) 62 - 120	105 (12) 84 - 130



\*p=0.05



For patient family maps:

	'Well adjusted' (n=20)	'Enmeshed' (n=16)	'Fractured' (n=11)
Self-identity exploration (mean, SD) - range	53.8 (7.2) 39 - 66	52.6 (8.3) 35 - 65	60.3 (8.3) * 46 - 73
Being able to talk about epilepsy (n, %)	15 (75%)	7 (44%)*	10 (91%)
Anxiety (mean, SD) - range	7.4 (3.7) 1 - 16	5.1 (3.4) 0 - 10	5.9 (4) 1 - 14
Depression (mean, SD) - range	5.0 (3.2) 1 - 10	3.7 (2.6) 0 - 8	5.1 (3.1) 0 - 12
Internal locus of control (mean, SD) - range	18.4 (4.3) 10 - 26	20.8 (5.0) 13 - 31	17.6 (3.8) 12 - 22

\* $p < 0.05$





'Well-adjusted' families  
(~50%) feel connected  
to one another.

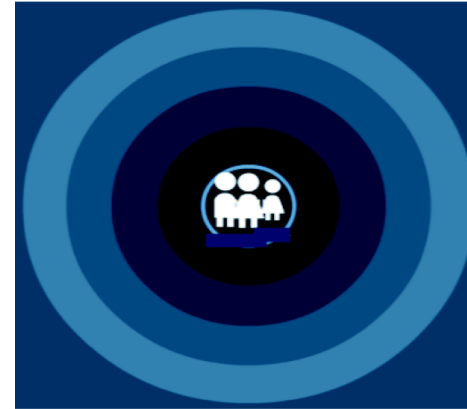
Patients see their family  
unit as flexible...

...they report good  
communication between family  
members, and feel satisfied  
with the support of their  
families.

A 'Well adjusted'



B 'Enmeshed'



C 'Fractured'



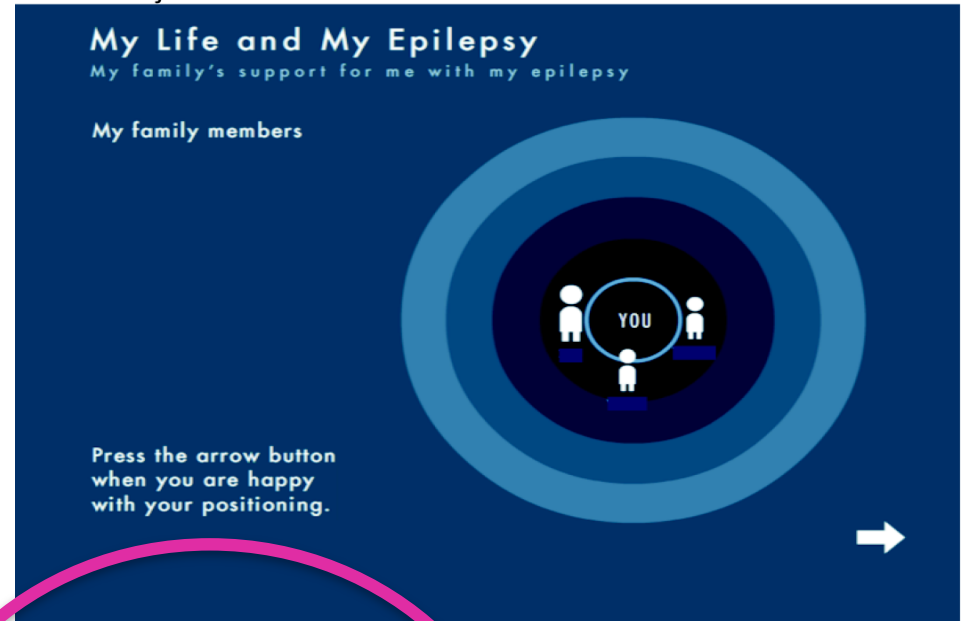


'Enmeshed' families  
(~30%) feel very  
connected to each other.

Patients feel closer to their  
caregiver than in other families...

...but feel less able to  
talk about their epilepsy  
(there is less family  
flexibility).

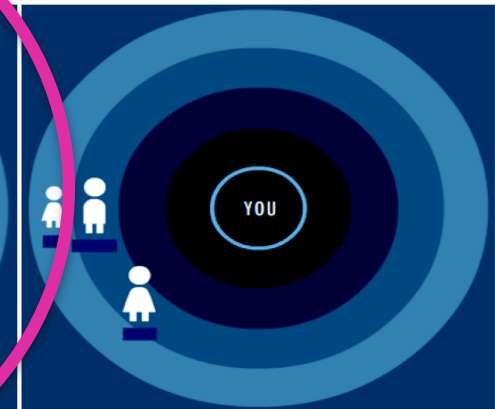
A 'Well adjusted'



B 'Enmeshed'

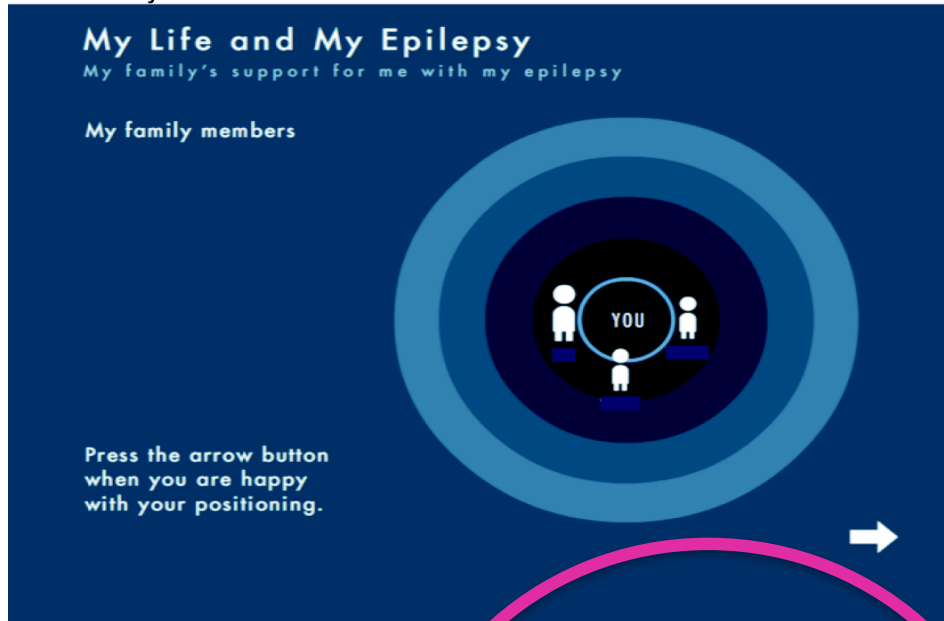


C 'Fractured'

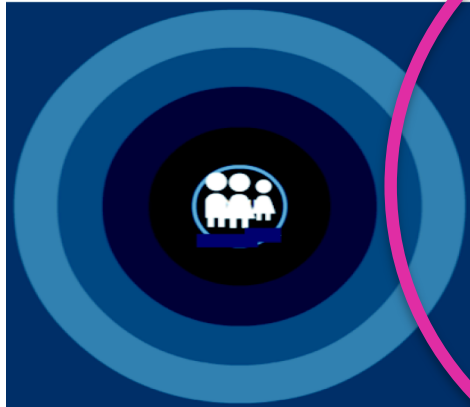




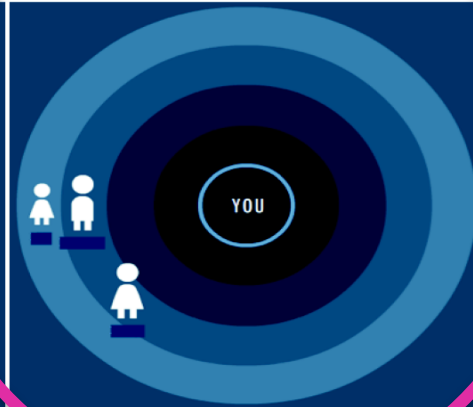
A 'Well adjusted'



B 'Enmeshed'



C 'Fractured'



'Fractured' families (~20%) are the least cohesive and connected.

Patients feel disengaged...  
...that their family is inflexible... and that communication is poor.

They are the least satisfied with their families.

Patients are younger at epilepsy onset (early teens) and have higher self-identity exploration.



THE UNIVERSITY OF  
MELBOURNE

Thank-you!

## Collaborators:

Jeanette Lawrence

Genevieve Rayner

Staff, patients & families at the Austin CEP



THE UNIVERSITY OF  

---

MELBOURNE