Family functioning in people with medically refractory epilepsy

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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

(Ellis et al, 2000)
Living with Epilepsy

Experiencing epilepsy and its treatment
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

Mary
George
Susie
John

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

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
87 people

50 people with epilepsy
  - 32 temporal lobe focus
  - 18 extratemporal focus

37 caregivers
  - 16 mothers
  - 1 father
  - 16 spouses/partners
  - 2 siblings
  - 2 children

People with medically refractory focal epilepsy
- consecutively recruited through the CEP at Austin Health
### Who participated?

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

* *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

Example of patient map
Concordant ‘enmeshed’ family maps

Example of mother’s map (patient)  Example of adult daughter’s map (caregiver)
Type 3: ‘Fractured’

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)

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

*p≤0.05; **p<0.01

Provides good convergent validity for the interactive computer software
### What epilepsy factors are important?

**For patient family maps:**

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

*p=0.05*
For patient family maps:

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

*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.
‘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).

Conclusions
‘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.
Collaborators:
Jeanette Lawrence
Genevieve Rayner

Staff, patients & families at the Austin CEP