Pilot study: impact of Cystic Fibrosis on emotional and marital satisfaction

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Life expectancy in Cystic Fibrosis (CF) patients regularly increases. This progress opens new perspectives for life. Living in couple becomes an accessible project. We prospectively studied in adult patients the impact of CF on emotional adjustment (anxiety and depression) and marital satisfaction. Secondly we analysed links between these variables.

This project was conducted with self-administered questionnaires sent to twenty seven patients and spouses if both agreed with the informed consent. These questionnaires analysed: marital satisfaction (Dyadic Adjustment Scale) and emotional adjustment (The Hospital Anxiety and Depression Scale). CF severity was determined according to twelve criteria that included medical severity and treatment load. Twelve patients presented a severe form of the disease.

Although patients and spouses expressed a significant anxiety and depression, CF severity including treatment load was a factor that affected neither marital adjustment nor anxiety-depression. Furthermore, couples displayed the same profile of satisfaction.

This pilot study confirmed that the severity of the disease by itself is not the main factor that influences couples quality of life. Supported by: Association Vaincre la mucoviscidose.

Anxiety and depression in CF patients’ fathers and mothers

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Background: Chronic illness is a difficult condition for patients but for their parents also. Cystic fibrosis (CF) is multisystem disease that can represent a risk for the emotional status and quality of life of patients or their family members.

Aims: To assess the emotional status in the parents of patients with CF.

Methods: We administered the Hospital Anxiety and Depression Scale (HADS) questionnaire to a. 56 caregivers (32 mothers 24 fathers) of 34 children 0–11 years (mean age 4.6±3.8 yrs) (group A); b. 23 caregivers (13 mothers 10 fathers) of 16 teens 12–17 years (mean age 14.7±1.5 yrs) as well as to the teens themselves (group B).

All patients had a normal lung function (mean FEV1 94% and 84% pred. in group A and group B respectively).

Results: See the table. There was no relationship between patient clinical status and parent emotional status.

<table>
<thead>
<tr>
<th>Group</th>
<th>Absent</th>
<th>Moderate</th>
<th>Clinically relevant</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Absent</td>
</tr>
<tr>
<td>Group A</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fathers</td>
<td>56.5%</td>
<td>26.1%</td>
<td>17.4%</td>
<td>65.2%</td>
</tr>
<tr>
<td>Mothers</td>
<td>37.5%</td>
<td>31.3%</td>
<td>31.2%</td>
<td>65.6%</td>
</tr>
<tr>
<td>Group B</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fathers</td>
<td>60%</td>
<td>30%</td>
<td>10%</td>
<td>80%</td>
</tr>
<tr>
<td>Mothers</td>
<td>15.3%</td>
<td>46.2%</td>
<td>38.5%</td>
<td>46.1%</td>
</tr>
</tbody>
</table>

Conclusions: Mothers had significantly more critical depression in comparison to fathers (p<0.5) only in group B. This finding was not associated to clinical status of patients. To assess the mothers’ personal structure and to provide them with a specific psychological support could be very important in the management of CF.

Emotional condition of adult with cystic fibrosis (CF): implication of illness or structure of personality?

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Background: Living with chronic illness like cystic fibrosis (CF) represent a daily difficult condition for patients.

Aims: To compare the different emotional feel in adult males and females with CF and to correlate anxiety and depression with their clinical status.

Methods: We administered the Hospital Anxiety and Depression Scale (HADS) questionnaire to 52 adults: 22 males (mean age: 30.2±9.9 yrs) and 30 females (mean age: 27.4±6.7 yrs).

The mean FEV1 was 50.2±23.9% pred. in males and 63.4±28.8% pred. in females.

Results: Anxiety was absent, moderate or clinically relevant in 62%, 14%, 24% of males and 62%, 17%, 21% of females respectively. Depression was absent, moderate or clinically relevant in 76%, 5%, 19% of males and 79%, 6%, 21% of females, respectively. There was no significant relationship between emotional clinical status in our sample.

Discussion: We found a similar emotional condition in males compared to females, although lung disease was different in the two groups. Our results suggest to investigate the differences in disease severity perception and coping strategies between female and male adults with CF. Moreover, a specific psychological support seems to be more necessary for females than for males.

Self-care: a qualitative study of adults with CF

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Objective: To explore how a sample of adults with CF negotiate the (often) competing demands of body and society to achieve self-care.

Method: A representative sample of 40 (M=20; F=20) participants were selected by specialist healthcare staff. They were then interviewed and analysed using qualitative (narrative and dialogic) methods.

Results: At the one extreme 6/40 participants presented as passive and ‘hyper-compliant’. Dependent on supportive others and having few social responsibilities these demonstrated little need or desire to negotiate self-care in everyday life. At the other extreme 4/40 ‘radically non-compliant’ participants were also inactive but presented as socially withdrawn and with no support. Between these two groups, 30/40 participants actively negotiated conflicting aspects of body and society to achieve self-care. Of these, however, 7/40 ‘non-compliant’ participants achieved this by normalising treatment while 10/40 ‘compliant’ participants tended to medicalise it. The remaining 13/40 concordant participants tailored their treatment to maintain a health-life balance.

Conclusion: These 5 distinct styles of self-care suggest a range of ‘self’ constructions, each with their own internal logic. Compliance, concordance and non-compliance should therefore be regarded as distinct and equally valid modes of managing and accounting for self-care. It is clear, moreover, that styles of self-care inactivity also need to be recognised so as not to push patients further into the margins of the healthcare system. Not everyone with CF values the increasingly marginal role of the healthcare system. Not everyone with CF finds the increasing intervention and support provided by a specialist healthcare staff to be helpful or necessary.