Prevalence of Chronic Illnesses

1. Approximately 1 in 2 American adults live with at least one chronic illness. Approximately one-fourth of persons living with a chronic illness experience significant limitations in daily activities (WHO, 2009).

2. It is estimated that upwards of 27% of children in the United States have an existing chronic illness (Med, Pai, Hommel et al., 2012).

3. The prevalence of chronic illnesses is growing, and those with a chronic illness can expect to live longer as research and new technologies grow.

Chronic Illness and Psychosocial Interventions

1. The adolescent age is a crucial developmental window for children to learn and take ownership of their illness and treatment protocol (LaGreca et al., 1995).

2. There is a significant proportion of children that struggle to achieve this developmental milestone, which leads to preventable negative outcomes (Dashiff et al., 2005; Kuhn, Dikelberg & France, 2014).

3. Helping these adolescents achieve this milestone requires a multi-systemic approach.
What we know about psychosocial interventions

- There are 3 very useful meta-analyses
  - Barlow & Ellard, 2004
  - Beale, 2006;
  - Eccleston et al., 2012

- Summary conclusions
  - Psychosocial interventions can improve the HRQL of the Individual
  - Psychosocial interventions can improve adherence
  - Psychosocial interventions can reduce stress (self report and biological)
  - Psycho ED, CBT and individual approaches are effective pre to post. But lack 3 month sustainability
  - Family systems/engagement improve sustainability of effects

Introduction to MEND

- MEND is an intensive outpatient program that addresses the psychosocial stressors experienced by patients and their families in order to improve overall health related quality of life.
- Based on an ecological, family systems, and bio-behavioral stress response conceptual frameworks [see Distelberg et al., 2014]
Psychosocial Issues Among Children and Adolescents With Chronic Conditions

Psychological Adjustment
- Behavioral and emotional problems
- Low self-esteem
- Psychiatric disorders
- Sleep disorders affecting daytime performance and behavior

Social Adjustment
- Social adjustment problems
- Effects of illness on growth and development
- Difficulties in peer relationships
- Participation in peer activities (e.g., clubs, sports)

School Adjustment and Performance
- Effects of illness or treatment on cognitive functioning
- Fatigue
- Effects of treatment on central nervous system function
- Absenteeism

Treatment Adherence

Child Abuse Statistics

Children with special health care needs are:
- 3.76 times more likely to be neglected
- 3.79 times more likely to be physically abused
- 3.14 times more likely to be sexually abused
Effects of Chronic Illness on Siblings

• Meta analyses found negative overall effects for siblings of chronically ill children, particularly negative psychological effects related to adjustment (Sharpe & Rossiter, 1995 and Williams, 1997).

Siblings reported a higher risk for:

• Internalizing & externalizing behaviors
• Lower social competence
• Withdrawal and shyness
• Somatic complaints
• Behavioral problems & anger
• Poor peer relations or delinquency
• Feelings of loneliness & isolation
• Anxiety and depression
• Vulnerability and worry
• A decrease in school grades

Effects of Chronic Illness on Family Finances

• Family Finances increase due to chronic illness

  • Increases include:
    • Medication costs
    • Care Giving costs
    • Removal from the work force to care for a child or reduction in work hours for one parent

    • Chronically ill children required significantly more care time 7.8 hours a day
    • Paid care accounted for 8% to 16% of care time.
    • Annual costs = $25,900 per chronically ill child for the family
    • Estimated national annual costs are $155 to $279 billion for chronically ill children.

• Wilson et al., 2005
Effects of Chronic Illness on Marriage

- Literature indicates that couples with children with a chronic illness at significant risk for marital distress (Gordon Walker and Manion, 1991)
- Can stress the marriage and increase risk for separation of divorce (Perrin, Gnanasekaran, and Delahaye, 2012)
- Can also impact the mental health of parents (Perrin, Gnanasekaran, and Delahaye, 2012)
- Literature identifies:
  - Conflict
  - Role incongruity
  - Poor communication
  - Lack of intimacy and positive affect
    - (Barbarin, Hughes, and Chesler, 1985)

MEND therapy

- Intensive Outpatient Program
- Utilizes Peer-Group, Multifamily, Individual, and Family Therapy
- Improves Multidimensional Health Related Quality of Life Outcomes
- Evidenced Based: results published 13 peer reviewed journals to date
- 1st and 2nd Order Change Outcomes
- Foundational Principles:
  - Ecological levels of influence on the patient’s stress response pattern
  - Interception and Introspection
  - Shifting patterns through shifting meaning...
- Phasic process (continuous, mutually reinforcing)
  - Phase I: Orientation, Assessment, and Language
  - Phase II: Introspection and Congruence
  - Phase III: Meaning and Expression
  - Phase IV: CHANGE generalization and reintegration
MEND Program Structure

Seven Weeks = 21 days (sessions)

<table>
<thead>
<tr>
<th>Time</th>
<th>Monday</th>
<th>Wednesday</th>
<th>Thursday</th>
</tr>
</thead>
<tbody>
<tr>
<td>3:30</td>
<td>Check-in Processing</td>
<td>Check-in Processing</td>
<td>Check-in Processing</td>
</tr>
<tr>
<td>4:30</td>
<td>Peer Groups</td>
<td>Peer Groups</td>
<td>Multi-Family Group</td>
</tr>
<tr>
<td>5:30</td>
<td>Interoception: Experiential Group Therapy</td>
<td>Multi-Family Group</td>
<td>Multi-Family Group</td>
</tr>
<tr>
<td>6:30</td>
<td>Parent Education</td>
<td>Multi-Family Group</td>
<td>Multi-Family Group</td>
</tr>
</tbody>
</table>

MEND Team

The Team:
- Therapists (LMFT, LPCC, L PYSCH etc)
- Nursing
- MD (Psychiatrist)
- Referring physician
- Case managers
- Occupational Therapist
- Chaplains
MEND: What’s Unique?

1. Family inclusion (multi-family groups and parent support)
2. All illnesses together
3. Truly integrated care
4. Ecological and family systems framework

MEND Patients

- MEND has served over 23 different chronic illnesses
  - Type I Diabetes
  - Kidney Diseases
  - Organ Transplants
  - Cancers
  - Asthma
  - Cystic Fibrosis
  - Seizure
  - etc
- MEND will take any patient who has a chronic condition and where there are psychosocial stressors present.
- Recent study shows no difference in outcomes by chronic illness (Distelberg, Allen, Vaswani, Tapanes, Fokas, Lalas, 2018)

MEND Referral Process

[Diagram showing the referral process with steps such as Intake, MEND 21 session, Measure, Psych-Social, Med-Check, Head to Toe, etc.]

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Evidence from MEND studies:

1. Preliminary Chart Review Study

2. Prospective Intervention Study

3. Cost Benefit Analysis

4. Chronic Illness Outcome Comparisons

Initial Chart Review Study

Child Outcomes:
All child outcomes saw a significant decrease in problems associated with their chronic illness (with effect sizes ranging between $r^2 = .18$ - $r^2 = .64$).

These measures ranged from problems in:
1. Physical Functioning
2. Emotional Functioning
3. Social Functioning
4. Cognitive Functioning
5. Psychosocial Functioning
6. Days of school missed (reduced by 80%)
Initial Chart Review Study

MEND Improvements in Health Related Quality of Life

<table>
<thead>
<tr>
<th>Domain</th>
<th>Measure</th>
<th>T1 M(SD)</th>
<th>T2 M(SD)</th>
<th>T3 M(SD)</th>
<th>F</th>
<th>Eta sq</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stress</strong></td>
<td>Catecholamine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dopamine (log)</td>
<td>2.37 (.24)</td>
<td>2.17 (.45)</td>
<td>2.19 (.31)</td>
<td>5.43*</td>
<td>.18</td>
<td></td>
</tr>
<tr>
<td>Epinephrine (log)</td>
<td>.96 (.34)</td>
<td>.88 (.37)</td>
<td>.77 (.35)</td>
<td>4.00*</td>
<td>.15</td>
<td></td>
</tr>
<tr>
<td>Norepinephrine (log)</td>
<td>1.40 (.30)</td>
<td>1.33 (.39)</td>
<td>1.28 (.32)</td>
<td>2.01†</td>
<td>.09</td>
<td></td>
</tr>
<tr>
<td>Level of Stress Scale</td>
<td>10.74 (2.08)</td>
<td>4.75 (1.21)</td>
<td>7.39 (1.40)</td>
<td>8.05***</td>
<td>.22</td>
<td></td>
</tr>
<tr>
<td><strong>Cognitive Abilities</strong></td>
<td>WASI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FSIQ</td>
<td>92.74 (13.2)</td>
<td>98.50 (13.2)</td>
<td>98.10 (13.7)</td>
<td>9.13***</td>
<td>.26</td>
<td></td>
</tr>
<tr>
<td>PRI</td>
<td>90.81 (13.6)</td>
<td>101.90 (15.6)</td>
<td>102.20 (15.6)</td>
<td>8.09***</td>
<td>.25</td>
<td></td>
</tr>
<tr>
<td>VCI</td>
<td>92.81 (13.4)</td>
<td>96.00 (13.4)</td>
<td>95.60 (11.7)</td>
<td>1.54</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Academics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily Point Average</td>
<td>12.00 (13.0)</td>
<td>10.00 (13.0)</td>
<td>10.00 (13.0)</td>
<td>1.00</td>
<td>.12</td>
<td></td>
</tr>
<tr>
<td>Math in School</td>
<td>7.00 (13.0)</td>
<td>6.00 (13.0)</td>
<td>6.00 (13.0)</td>
<td>1.00</td>
<td>.12</td>
<td></td>
</tr>
<tr>
<td><strong>Mental Health</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beck Anxiety</td>
<td>57.23 (12.80)</td>
<td>59.47 (11.71)</td>
<td>59.13 (11.10)</td>
<td>9.66***</td>
<td>.25</td>
<td></td>
</tr>
<tr>
<td>Beck Depression</td>
<td>55.33 (13.52)</td>
<td>50.60 (10.18)</td>
<td>50.57 (11.97)</td>
<td>4.17**</td>
<td>.13</td>
<td></td>
</tr>
<tr>
<td>Beck Self Concept</td>
<td>44.07 (11.21)</td>
<td>47.53 (13.84)</td>
<td>48.43 (11.15)</td>
<td>3.23*</td>
<td>.10</td>
<td></td>
</tr>
<tr>
<td><strong>HRQOL</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Child HRQL</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional QoL</td>
<td>39.54 (20.0)</td>
<td>58.39 (21.5)</td>
<td>58.87 (23.9)</td>
<td>14.95***</td>
<td>.33</td>
<td></td>
</tr>
<tr>
<td>Physical QoL</td>
<td>56.39 (23.7)</td>
<td>63.51 (28.4)</td>
<td>66.88 (29.7)</td>
<td>3.30*</td>
<td>.10</td>
<td></td>
</tr>
<tr>
<td>School/academic QoL</td>
<td>45.66 (18.1)</td>
<td>63.82 (19.1)</td>
<td>64.94 (20.8)</td>
<td>15.19***</td>
<td>.34</td>
<td></td>
</tr>
<tr>
<td>Social QoL</td>
<td>56.53 (28.4)</td>
<td>72.74 (19.9)</td>
<td>72.10 (23.8)</td>
<td>7.70***</td>
<td>.20</td>
<td></td>
</tr>
<tr>
<td><strong>Family Functioning</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>40.08 (25.7)</td>
<td>58.06 (23.3)</td>
<td>58.92 (25.3)</td>
<td>16.99***</td>
<td>.35</td>
<td></td>
</tr>
<tr>
<td>Rejection</td>
<td>40.08 (25.9)</td>
<td>58.06 (24.9)</td>
<td>58.92 (25.3)</td>
<td>16.99***</td>
<td>.35</td>
<td></td>
</tr>
<tr>
<td>Responsibility</td>
<td>45.88 (25.7)</td>
<td>64.83 (28.3)</td>
<td>65.81 (27.3)</td>
<td>5.80*</td>
<td>.17</td>
<td></td>
</tr>
<tr>
<td>Love</td>
<td>45.48 (25.8)</td>
<td>78.30 (15.8)</td>
<td>84.10 (20.9)</td>
<td>17.11***</td>
<td>.36</td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td>47.02 (25.7)</td>
<td>78.42 (23.6)</td>
<td>84.10 (22.2)</td>
<td>17.11***</td>
<td>.36</td>
<td></td>
</tr>
</tbody>
</table>

FSIQ = WASI subscale for general cognitive ability, PRI = WASI subscale for nonverbal fluid abilities and visuomotor/coordination, VCI = WASI subscale for crystallized abilities, HRQOL = Health Related Quality of Life

† = p < 0.1, * = p < 0.5, ** = p < 0.01, *** = p < 0.001
MEND Effects: 24 Hour Urine Catecholamine Measures

- Baseline (n = 20)
- Post Test (n = 7)
- 3 Month Post Test (n = 4)

± standard error interval

Norepinephrine
Epinephrine

Prospective Intervention paper

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Cost Benefit Analysis

MEND: 21 sessions = $5,320

<table>
<thead>
<tr>
<th></th>
<th>Pre-MEND</th>
<th>Post-MEND</th>
<th>Change Pre-MEND to Post-MEND</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$20,924</td>
<td>$5,675</td>
<td>$15,248</td>
</tr>
</tbody>
</table>

Results of the Repeated Measures T-tests of Medical Record Expenses Pre- and Post-MEND (N=20)

In Direct Benefits

<table>
<thead>
<tr>
<th>Item</th>
<th>Benefit in one month</th>
<th>Benefit after 12 months</th>
<th>Estimated cost per unit</th>
<th>Total annual benefit per patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced number of missed days of work</td>
<td>1.00</td>
<td>5.00</td>
<td>$216.36</td>
<td>$11,683.44</td>
</tr>
<tr>
<td>Reduced number of days a caregiver is needed</td>
<td>3.13</td>
<td>7.07</td>
<td>$95.42</td>
<td>$3,583.98</td>
</tr>
<tr>
<td><strong>Indirect benefit subtotal</strong></td>
<td><strong>$15,267.42</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Direct benefit subtotal</strong></td>
<td><strong>$15,248.00</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total Benefit</strong></td>
<td><strong>$30,515</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a Estimated daily wage based on the Bureau of Labor Statistics 2013 average hourly wage for the state of California ($15.03) and rounded to the nearest cent. Estimated cost per unit based on 2018 median household income of $54,090 from census 2013 data. Per day wage = $54,090 / 250 working days.

Summary

• Family Systems intervention can improve the HRQL of chronically ill individuals

• These interventions also improve the QOL of the family/caregiver

• Family systems interventions can have indirect effects on biological markers of chronic illness and stress

• Family systems interventions offer greater sustainability in comparison to individual approaches

• These interventions might cost significantly more than other interventions, but CBA ratios demonstrate the net positive gain.

Contact

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