MEND: A MULTI-DIMENSIONAL FAMILY SYSTEMS BASED APPROACH TO CHRONIC ILLNESS

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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 (Modi, 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 an **crucial developmental window** for children to learn and take ownership of their illness and treatment protocol (La Greca 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, Distelberg & France, 2014)
3. Helping these adolescents achieve this milestone **requires a multi-systemic approach**

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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 sustainbility
  - Family systems/engagement improve sustainability of effects

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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-behavorial stress response conceptual frameworks (see Distelberg et al., 2014)

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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 (eg, 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

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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

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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

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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

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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)

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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
  - Interoception 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

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MEND Program Structure

Seven Weeks = 21 days (sessions)

M.E.N.D. Program: Adolescent Treatment Schedule			
Time	Monday	Wednesday	Thursday
3:30 - 4:30	Check-in Processing	Check-in Processing	Check-in Processing
4:30 - 5:30	Peer Groups	Peer Groups	Peer Group
5:30 – 6:30	Multi-Family Group	Interoception: Experiential Group Therapy Art Therapy Music Therapy	Multi-Family Group
M.E.N.D. Program: Adolescent Parent Schedule			
4:30 – 5:30	Parent Education		Parent Education
5:30 – 6:30	Multi-Family Group	Parent Support	Multi-Family Group

MEND Team

The Team:

- Therapists (LMFT, LPCC, L PYSCH etc)
- Nursing
- MD (Psychiatrist)
- Referring physician
- Case managers
- Occupational Therapist
- Chaplains

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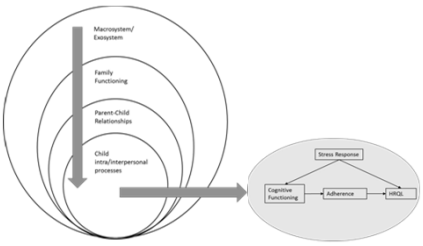
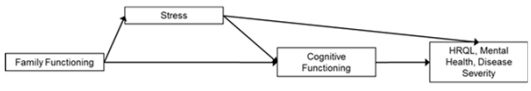
MEND Theory





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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
  - Cytic 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)

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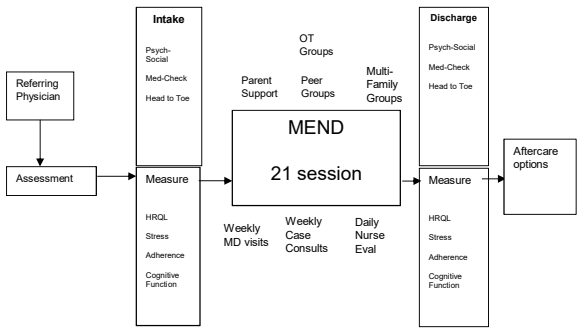
MEND Referral Process



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Evidence from MEND studies:

1. Preliminary Chart Review Study
   Distelberg, B., Williams-Reade, J., Tapanes, D., Montgomery, S. & Pandit, M. (2014). Evaluation of a Family Systems Approach to Managing Pediatric Chronic Illness: Managing Each New Direction (MEND). Family Process, 53(2), 194-213 DOI:10.1111/famp.12066
2. Prospective Intervention Study
   Distelberg, B., Tapanes, D., Emerson, ND., Brown, WN., Vaswani, D., Williams-Reade, J., Anspikian, A. & Montgomery, S. (2017). Prospective Pilot Study of the MEND Psychosocial Family Systems Program for Pediatric Chronic Illness. Family Process, DOI: 10.1111/famp.12288
3. Cost Benefit Analysis
   Distelberg, B., Emerson, ND., Gavaza, P., Tapanes, D., Brown, WN., Shah, H., Williams-Reade, J., Montgomery, S. (2016). A cost benefit analysis of a family systems intervention for managing pediatric chronic illness. Journal of Marital and Family Therapy. DOI: 10.1111/jmft.12166
4. Chronic Illness Outcome Comparisons
   Distelberg, B., Allen, J., Tapanes, D., Vaswani, D., Lalas, S., & Montgomery, S. (In Review). Using a psychosocial intervention for pediatric chronic illnesses across disease groups: Can it be done? Family Process

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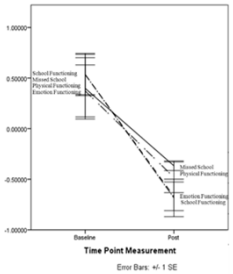
Initial Chart Review Study



Child Outcomes:

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

Distelberg, Williams-Reade, Tapanes, Montgomery & Pandit, 2014

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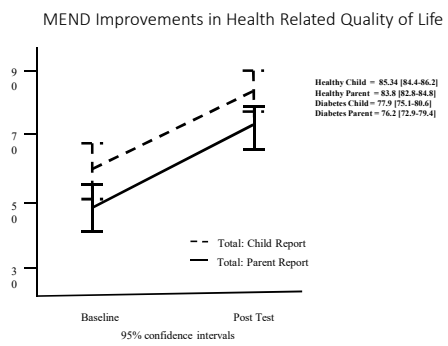
Initial Chart Review Study



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Prospective Intervention paper

Domain	Measure	T1 M(SD)	T2 M(SD)	T3 M(SD)	$F_{(2,60)}$	Eta-sq
Stress	Catecholamine					
	Dopamine (log)	2.37(.24)	2.17(.45)	2.19(.31)	5.43*	.18
	Epinephrine (log)	.96(.34)	.88(.37)	.77(.35)	4.00*	.15
	Norepinephrine. (log)	1.40(.30)	1.33(.39)	1.28(.32)	2.01†	.09
	Level of Stress Scale	10.74(2.08)	4.75(1.21)	7.39(1.40)	8.05***	0.22
Cognitive Abilities	WASI					
	FSIQ	92.7(13.2)	98.5(13.2)	98.1(13.7)	9.13***	0.24
	PRI	94.8(14.2)	101.9(15.6)	102.2(15.6)	8.80***	0.23
	VCI	92.8(13.4)	96.0(13.4)	95.6(11.7)	1.54	
Academics						
	Grade Point Average	2.94(0.80)	3.00(.73)	3.29(.66)	3.24*	0.15
	Missed days of school	10.28(9.94)	1.48(2.34)	1.69(3.23	19.26***	.41
	Sick Days	7.93(9.88)	2.69(5.63)	2.03(3.21)	9.04***	.24
Mental Health	Beck Anxiety	57.23(12.80)	49.47(11.71)	49.13(11.10)	9.66***	.25
	Beck Depression	55.33(13.52)	50.60(10.18)	49.57(11.97)	4.18**	.13
	Beck Self Concept	44.07(11.21)	47.53(13.84)	48.43(11.15)	3.23*	.10
HRQOL	Child HRQL					
	Emotional QoL	39.54(20.0)	58.39(21.5)	58.87(23.9)	14.95***	.33
	Physical QoL	56.39(23.7)	63.51(28.4)	66.88(29.70)	3.30*	.10
	School/Academic QoL	45.66(18.1)	63.82(19.1)	64.94(20.8)	15.19***	.34
	Social QoL	56.53(28.4)	72.74(19.9)	72.10(23.8)	7.70***	.20
Family Functioning						
	Communication	60.00(25.7)	68.06(21.1)	76.39(24.1)	6.42***	.19
	Emotion	45.00(24.8)	63.67(25.6)	70.17(27.5)	13.95***	.33
	Relationship	55.00(27.4)	64.33(20.8)	68.83(23.3)	5.40***	.17
	Social	63.69(28.2)	73.33(23.5)	81.67(20.8)	10.16***	.26
	Worry	37.83(25.7)	58.79(25.4)	63.67(25.6)	15.42***	.35

FSIQ = WASI subscale for general cognitive ability, PRI = WASI subscale for nonverbal fluid abilities and visuomotor coordination, VCI = WASI subscale for crystallized ability, HRQOL = Health Related Quality of Life
*† = p < 0.1, * = p < 0.5, **p < 0.01, *** = p < 0.001*

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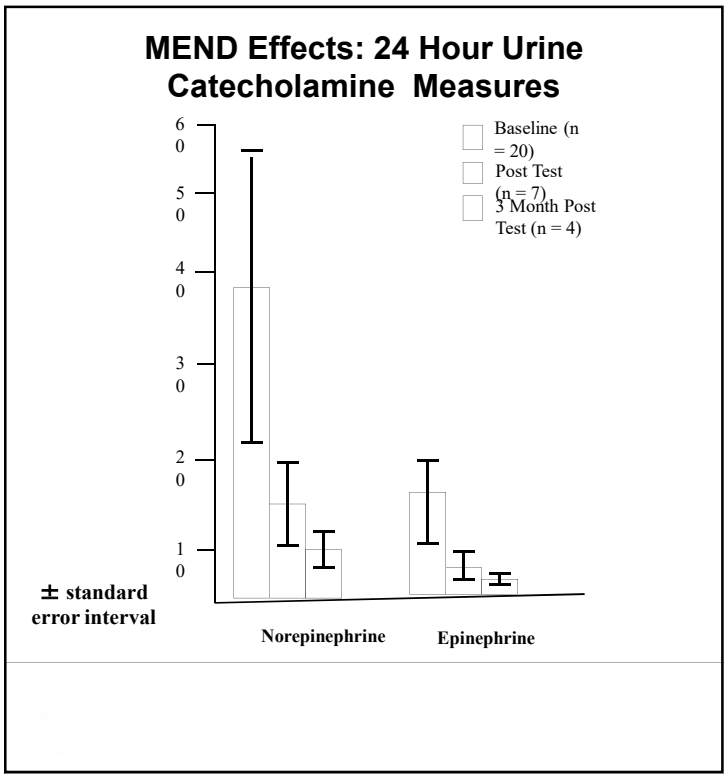

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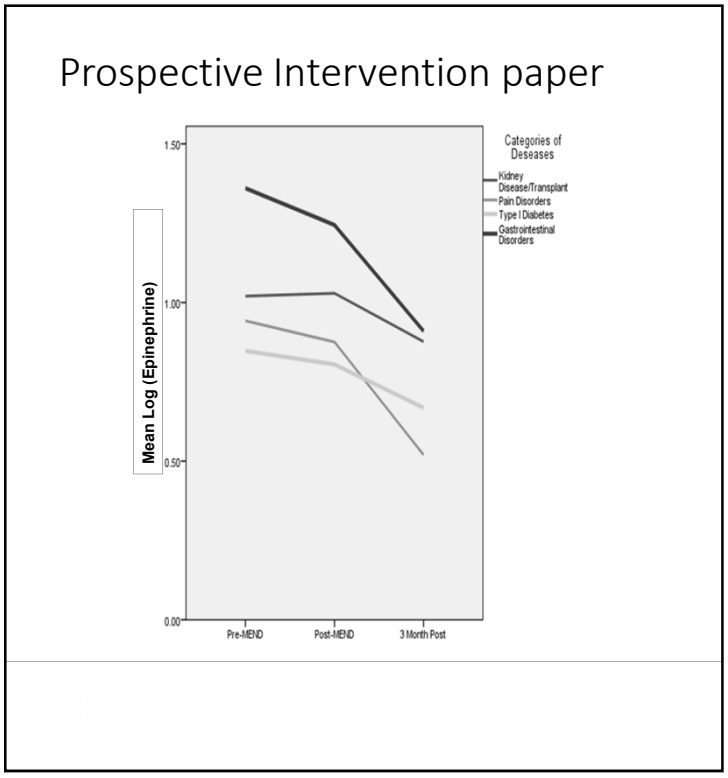

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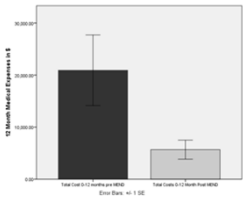
Cost Benefit Analysis

MEND: 21 sessions = $5,320

Pre-MEND			Post-MEND			Change between Pre- and Post-MEND		t(df)
SD	Q1-Q3		*SD*	Q1-Q3		*M*	*SD*	
$20,924	(27,973)	2,906-24,270	$5,675	(7,543)	411-6,899	-$15,248	(28,800)	2.18* (16)

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



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Cost Benefit Analysis

In Direct Benefits

	Pre-MEND		Post-MEND		3 Months-Post		
		SD		*SD*		*SD*	
Indirect Costs/Benefits							
Missed Days of Work (one month)	5.00	(7.91)	0.50	(1.07)	0.38	(1.06)	$F_{(2,40)} = 4.94$, $p < 0.01$, $\eta^2 = .38$
Days a Caregiver is Needed (one month)	10.20	(12.64)	7.07	(11.58)	3.13	(7.94)	$F_{(2,40)} = 6.31$, $p < 0.01$, $\eta^2 = .25$
Auxiliary Measures							
Number of Hospital Stays (one year)	1.95	(2.41)	1.58	(2.52)	1.37	(4.11)	$F_{(2,40)} = 3.14$, $p < 0.05$, $\eta^2 = .14$
Number of ER visits (one year)	2.42	(2.07)	1.42	(2.81)	0.42	(0.51)	$F_{(2,40)} = 7.11$, $p < 0.05$, $\eta^2 = .40$
Missed Days of School (one month)	12.53	(12.11)	1.60	(3.02)	1.73	(3.15)	$F_{(2,40)} = 20.92$, $p < 0.001$, $\eta^2 = .54$

Means (M) and Standard Deviations (SD) represented in the table are based on non-transformed raw data. The ANOVA F and effect size is based on the natural log transformed data.

Items	Benefit in one month	Benefit after 12 months	Estimated cost per unit	Total annual benefit per patient
Reduced number of missed days of work	4.50	54.00	$216.36[a]	$11,683.44
Reduced number of days a caregiver is needed	3.13	37.56	$95.42[b]	$3,583.98
			Indirect benefit subtotal	$15,267.42
			Direct benefit subtotal	$15,248.00
			Total Benefit	$30,515

[a]Estimated daily wage based San Bernardino median household income of $54,090 from census 2013 data. Per day wage = 54.090/250 working days per year.
[b]Estimated daily caregiver costs based on annual cost of child care from the National Association of Childcare Resources & Referral Agencies (2015) (median annual wage = $24,810.

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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.

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