

Caregivers of Children with PANS Need Care

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Parents



“
You always
have to carry
on. And you
can, because
you have to.”





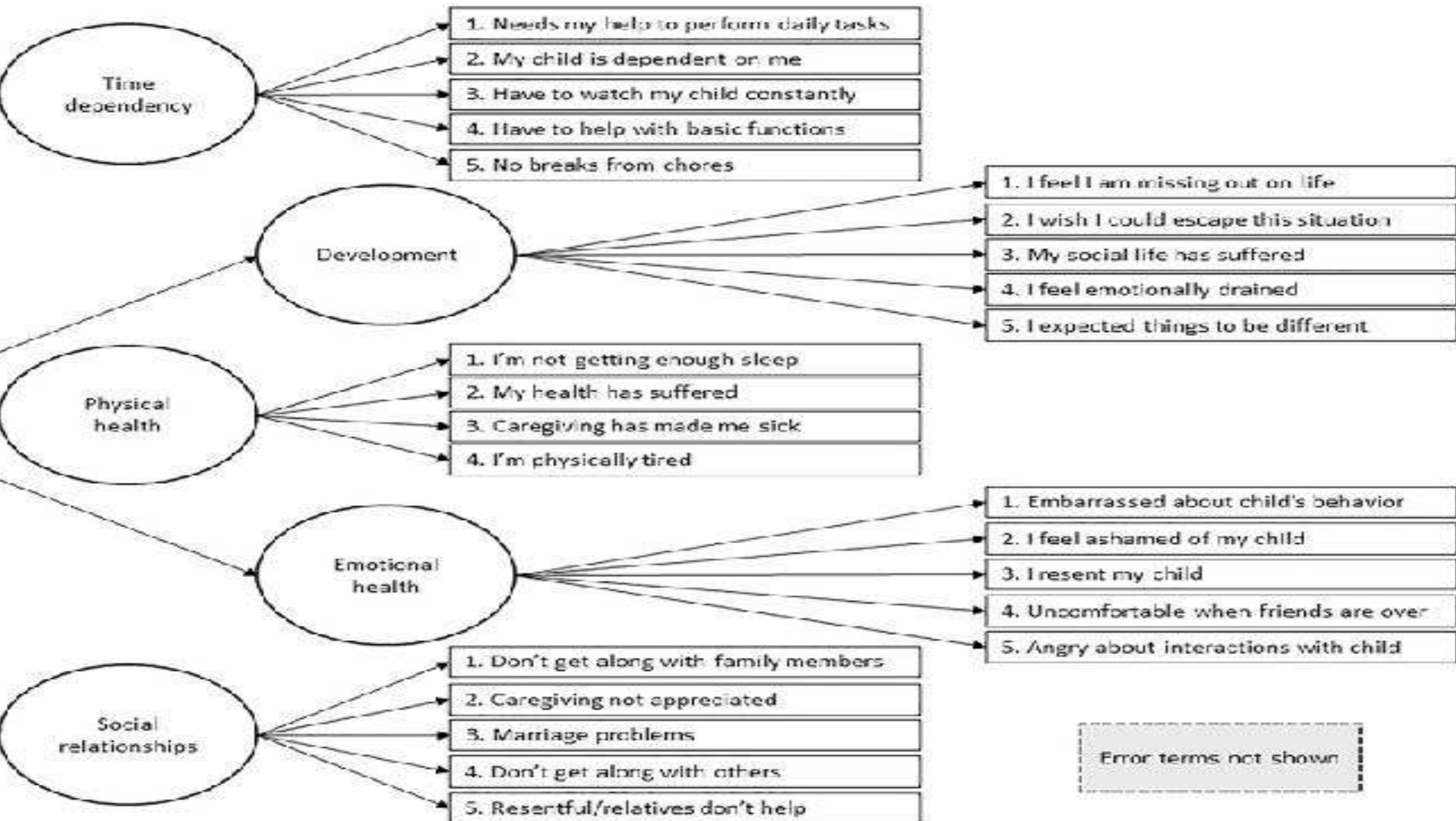
The Burden is Heavy

Intervention with parents has the potential to help

- parent/child relationship
- parents' navigation of the
 - medical system
 - educational system
- parents' emotional and physical well-being
 - teach skills
 - let parents communicate without feeling judged and misunderstood
 - decrease sense of isolation
 - acknowledge parents' sacrifices

Caregiver burden and the associated factors in the family caregivers of patients with schizophrenia
[Farnaz Rahmani](#), [Fariborz Roshangar](#), [Leila Gholizadeh](#), [Elnaz Asghari](#)
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<https://doi-org.laneproxy.stanford.edu/10.1002/nop2.1205>





Parents asked for help

- We adapted and rewrote a manual designed for addressing trauma in parents of newborns in the NICU for parents of PANS patients.
- We piloted, studied, and bootstrapped group psychotherapy protocols for parents.
- Team of (talented!) Palo Alto University psychology graduate students:
 - Hannah Ellercamp
 - Jason Tinero
 - Stephanie Glover
- Four 10-12 week sessions over 2 years
- 29 parents with data

Manualized Group Offered:

- Support and Sharing experiences
- Psychoeducation
 - What is PANS
 - How much, how little is known about treatment, etc
- Coping Skills
 - Healthy, such as actively approaching problems, self care, seeking social support
 - Unhealthy, such as substance use, denial, social withdrawal
- Cognitive Restructuring
 - Reappraisal of distortions:
 - “I am the worst father in the world”
 - “This is all my fault”
 - “If only I had or hadn’t....”
- Positive Psychology:
 - Notice things about which one is grateful
 - Gratitude Journal
 - Notice things that DID go well
 - Victories Over PANS observations
- Stress Coping
 - Identifying Stress Reactions: Physical, Emotional, Behavioral
 - Stress Reduction Skills
 - Mindfulness meditation
 - Progressive muscle relaxation
 - Self care: eating, exercise, social support
- Trust:
 - Reducing All-or-Nothing thinking
 - (I don’t trust my doctor to get me to a PANS specialist, and I do trust that doctor to care for my other well child’s routine care)
- Grieving
 - Identifying losses (dreams, expected social interactions, own projects, time with others...)
 - Identifying “stuck points” such as over-blown sense of responsibility
- Radical Acceptance
- Dialectical Thinking:
 - AND not Either/Or
 - (I am so stress I hardly feel like I know what I am doing AND I am doing a good job with my child)
- Writing a Trauma Narrative
- Letter to the Child



10-12 Week Manualized Group Offered:



- Support and Sharing experiences
- Psychoeducation
 - What is PANS?
 - What is known/unknown about treatment, etc?
 - How is it to have a child with an illness without a proven roadmap for treatment?
- Coping Skills
 - Healthy
 - actively approach to problems, self care, seeking social support
 - Unhealthy
 - substance use, denial, social withdrawal
- Cognitive Restructuring
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- Coping Skills
- Cognitive Restructuring

- **Positive Psychology:**

- Noticing things about which one feels grateful improves mood
 - Gratitude Journal
- Notice things that DID go well
 - Victories Over PANS observations

- **Stress Coping**

- Identifying Stress Reactions:
 - Physical- muscle tension, aches
 - Emotional: irritability, fatigue
 - Behavioral: withdrawal, use of alcohol, etc, not exercising
- Stress Reduction Skills
 - Mindfulness meditation
 - Progressive muscle relaxation
 - Self care:
 - eating
 - exercise
 - social support



- Trust:
 - Reducing All-or-Nothing thinking
 - (I don't trust my doctor to get me to a PANS specialist, and I do trust that doctor to care for my other well child's routine care)
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 - Self care: eating, exercise, social support

- Trust:
 - Explore changes in one's trust about
 - The future
 - Healthcare
 - Friends, etc
 - Reducing All-or-Nothing thinking about trust
 - E.g. I don't trust my doctor to get me to a PANS specialist, and I do trust that doctor to care for my other well child's routine care
- Grieving
 - Identifying losses
 - Dreams
 - Expected social events (birthday parties, drop-off chat group, graduations, own projects, time with others, professional goals
 - Identifying "stuck points" interfering with grieving
 - Over-blown sense of responsibility
 - Guilt
 - If only....
- Radical Acceptance
- Dialectical Thinking:
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- Support and Sharing experiences
- Psychoeducation
- Coping Skills
- Cognitive Restructuring
- Positive Psychology:
- Stress Coping
- Trust:
- Grieving

- Radical Acceptance
 - Don't fight the reality, dwell, rage, fret, deny, withdraw
 - Dust off and say, "Okay. This is where we are. This is what it is. Now what do I need to do?"
- Dialectical Thinking: **AND** not *Either/Or*
 - I am so stressed I hardly know what I am doing **AND** I am doing a good job with my child.
 - Things have never seemed worse with my child **AND** he/she/they were incredibly kind today.
- Writing a Trauma Narrative
 - Choose one instance that felt traumatic and one avoids thinking about
 - Write in detail (all 5 senses...) about the event and what one felt
 - Read, reread the piece
 - Read to group if desire
- Letter to the Child
 - This could be for sharing now or at some later date
 - What you would like the child to understand (eg their bravery) Many children do not remember much about their flares.

Some parents had become significantly anxious, associated with their children's PANS

Anxiety:

- Before group therapy:
 - 10 of 29 parents suffered “moderate” or “higher” anxiety on the Beck Anxiety Inventory
- After group therapy:
 - 8 had improvement, 6 of those to “mild” anxiety.
 - 1 had no change, 1 had more anxiety
 - There was a significant difference in anxiety at baseline ($M=24.40$, $SD=4.42$) and post-group ($M=14.40$, $SD=11.00$); $t(9)=3.42$, $p=.008$.
- The other 19 patients did not endorse anxiety at baseline, and therefore, did not have room to improve.

Some parents had become significantly associated with their children's PANS

Depression:

- 18 of 29 participants endorsed “significant depression” on the Beck Depression Inventory at baseline.
- Post-group, 6 of them rated themselves as “minimally or not depressed”
- 5 of them endorsed decreased depression, but it still fell within the mild range or higher.
- 1 participant endorsed no change in depression.
- 4 participants endorsed increased depression.
- For those who endorsed high depression at baseline there was a significant difference in depression at baseline ($M=16.65$, $SD=5.09$) and post-group ($M=13.06$, $SD=9.07$); $t(16)=2.42$, $p=.028$.

Some parents noted trauma associated with their children's PANS

Trauma:

- 6 people endorsed significant trauma symptoms at baseline using a cutoff score of 31 (significant trauma) on the PTSD checklist PCL-5
- Post-group, 4 of them had decreased symptoms of trauma that fell below the cutoff.
- 1 participant had decreased symptoms but they still fell above the cutoff.
- 1 participant endorsed no change in trauma symptoms.
- For those who endorsed high symptoms of trauma at baseline there was a significant difference in traumatic symptoms at baseline ($M=40.33$, $SD=7.79$) and post-group ($M=27.17$, $SD=14.93$); $t(5)=2.65$, $p=.046$. Since this is quite a small sample size, this should be interpreted with caution.

Coping skills, Satisfaction

- Parents used better coping strategies as measured by the Brief COPE Inventory
 - Actively approaching problems
 - Acceptance
 - They also endorsed more disengagement, but we do not know specifically from what
- Parents were satisfied with the treatment: on weekly ratings, out of a possible 5,
 - Overall satisfaction as 4.7
 - Overall usefulness of techniques as 4.5
 - Timing and length of the sessions as 4.45

Parent feedback

Participants reported finding that the most helpful sessions were on:

- dialectical thinking,
- positive self-talk,
- psychoeducation about trauma
- trust

Parents indicated that they appreciated connecting with other parents of youth with PANS

Mixed group?

- Several parents shared that they both appreciated and found challenging having group members with children at
 - different developmental ages (school aged child vs. young adult)
 - different flare states (new, relapsing-remitting and chronic)

Thoughts about complex trauma and resilience



- Our model NICU manual dealt with a single trauma
- Our patients have repeated and continued trauma (complex trauma)
- Next groups might focus on *resiliency training*: like the military, parents have to go out and continue the mission
 - Research shows peer support helps resiliency
- Post-Traumatic Growth

Future directions: Empower parents to

- Be able to relax at will
- Recognize stress-inducing situations
- Restructure maladaptive thoughts
- Be assertive about needs
- Choose appropriate coping responses
- Find social support



To improve clinical practice:

- *You might say....:*
 - *Caregiving is a very hard job.*
 - *To provide the very best patient care, we need to include your needs in the care. Can you tell me how you are doing with these responsibilities?*
 - *Many caregivers don't want to burden others. Are there times when you need help but are reluctant to ask?*
- Remember to:
 - Counsel patients and caregivers on expected changes and prognosis of their underlying condition since many caregivers have limited experience on what is normal or expected.
 - Utilize the “teach back” method when providing caregiver information: *Can you explain that back to me so I can be sure I did a good job explaining it?*
 - Caregiver support groups (in-person or online), best if matched to condition of the patient.²¹
- Additional Recommendations
 - Caregiving skills training
 - Account for the needs of patients *and* caregivers when discussing treatment options.

