

Systems Factors in Families Coping with ASD: Marital and Parental Variables

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Edward G. Carr
1947 – 2009



How Well Has PBS Succeeded?

- Depending on the studies reviewed, between *one-half to two-thirds* of the individuals treated show at least 80-90% reduction in problem behavior from baseline (Carr et al., 1999)
- Why does problem behavior not improve or why do gains not maintain for 33-50% of individuals?
- Systems factors may play a role in lack of intervention gains or maintenance of gains

The Five-Term Contingency

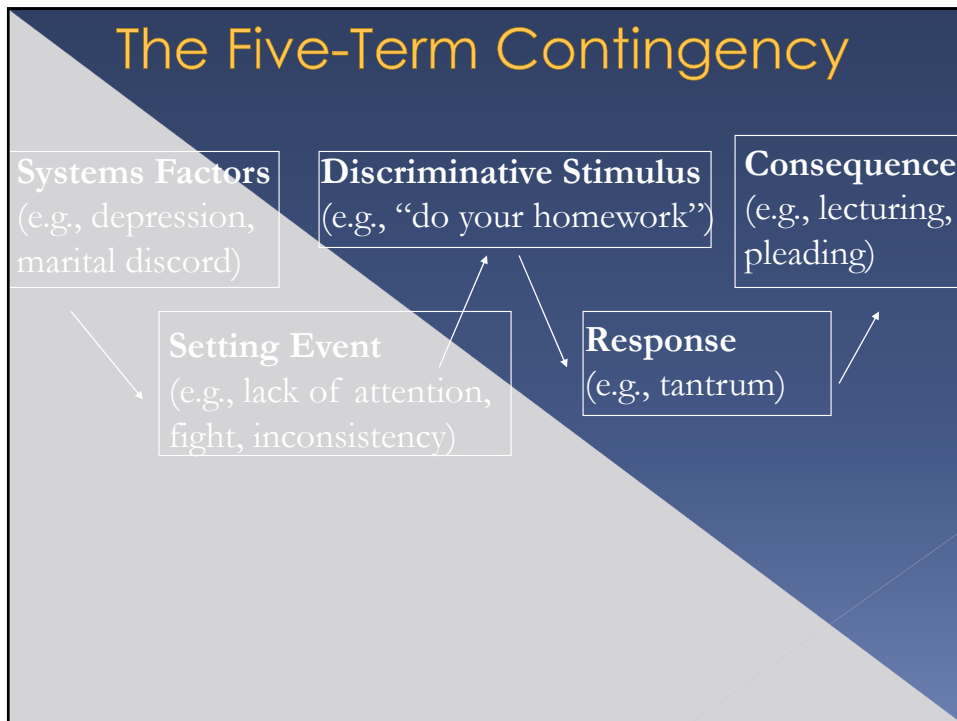
Systems Factors
(e.g., depression, marital discord)

Discriminative Stimulus
(e.g., “do your homework”)

Consequence
(e.g., lecturing, pleading)

Setting Event
(e.g., lack of attention, fight, inconsistency)

Response
(e.g., tantrum)



The Central DV in PBS: Quality of Life

- ◉ Quality of Life (QOL) = social relationships, employment, choice, autonomy, recreation & leisure, community adjustment skills, community integration opportunities
- ◉ QOL severely impacted by having a child with ASD, more so than other disorders (Lee et al., 2008)
- ◉ Problem behavior = Lower QOL for many families
- ◉ Improving QOL may help reduce problem behavior & reducing problem behavior may help improve QOL

The Central IV in PBS: Systems Change

- ◉ The central independent variable in PBS is systems change, as dysfunctional systems are one of the three classes of impediments to QOL (Carr, 2007)
- ◉ Thus, in order to reduce children's problem behavior and truly improve family quality of life in the long term, there is a need to acknowledge and address the wider family system

Why is this important?

- Traditional ABA/PBS focuses directly or indirectly on the child with ASD, while the psychological needs of parents and siblings or other family systems factors are typically ignored

Family Systems Factors

- Parenting stress
- Parental depression
- Marital satisfaction/marital discord
- Lack of paternal involvement
- Parental unemployment
- Divorce/single-parent families
- Sibling issues

Parenting Stress

- Parents of children with ASD often experience more parenting stress than parents of children with TD or other DDs
- May be due to decreased QOL related to factors such as:
 - Severe problem behavior
 - Exclusion from community
 - Isolation from family and friends

Baker-Ericzen et al. (2005); Dunn et al (2001); Holmes & Carr (1991); Holroyd & McArthur (1976); Kasari & Sigman (1997)

Psychological Factors

- Mothers of children with ASD report higher levels of depressive/anxiety symptoms (Gray & Holden, 1992).
- Mothers and fathers tend to feel less closeness in their relationship with their child.
- Child behavior problems linked to depressive symptoms (Baker & Blacher, 2005).
- Parents' stress continues into their child's adulthood.

Siblings of Children with Autism



Siblings

- Often overlooked in the research literature (and everywhere else)



Relationships Between Sibs

- Marital discord is predicted by the degree of problematic interactions between the child with ASD and their siblings (Rivers & Stoneman, 2004).

The Needs of Siblings

- Siblings of children with autism...
 - > Show higher rates of internalizing and externalizing disorder symptoms than sibs of typically developing children (Rivers & Stoneman, 2004).
 - > Appear particularly prone to responding to their siblings' symptoms, especially aggression, with anger (Ross & Cuskelly, 2006).
 - > Often receive less attention from parents, which commonly leads to problematic interactions with their siblings (McHale & Pawletko, 1992).

From the Child w/ ASD's Point of View

- Children with autism...
 - > Initiate more interaction with typically developing peers than with affected peers at school (Bauminger, Shulman, & Agam, 2003).
 - > Initiate more interaction with their siblings than they do with their parents or other children (El-Ghoroury & Romanczyk, 1999).



Intervention

- Inclusion of Siblings
 - > Training siblings to use behavioral strategies has shown success in causing behavior change in children with developmental disabilities (Colletti & Harris, 1976).
 - > Siblings have also been trained to use positive behavioral strategies when teaching their brother or sister new skills; at 6 month follow up they were still using these techniques and reported liking their sibling MORE (Schreibman, O'Neill, & Koegel, 1983).

Intervention, cont.

- Inclusion of siblings
 - › After being taught playtime skills by a sibling, children with autism showed more initiated play, play-related speech, and response to interaction. At 2 month follow-up, playtime between the siblings had increased (Celiberti & Harris, 1993).



Intervention, cont.

- Inclusion of siblings
 - › By using activities that include preferred topics for both siblings, ritualized behaviors and perseverative language has been shown to decrease (Baker, 2000).
 - › Use of video-modeling featuring siblings, has also increased play behavior (Taylor, Levin, & Jasper, 1999).
 - › SPECIAL NOTE: Without training the sibling in behavioral principles these strategies do not appear to last overtime (Tsau & Odom, 2006).

From the Sibs' Point of View

- Siblings think of their brother's or sister's condition
 - > Their report changes with developmental age and their inability to understand the disorder is often underestimated by parents (Glasberg, 2000).
 - > Like parents, siblings report feeling concern for their affected sibling's future (Mascha & Boucher, 2006).

Therapy for Siblings

- One study showed that family-based intervention that included educational groups for sibs resulted in increased connectedness between siblings (Lobato & Kao, 2005).
- **Most groups are recreational/supportive, without psychoeducation, skills training or a psychotherapy component.**

Future Directions

- Siblings may be an ideal helper in behavior management of their siblings!
- Siblings may require services for their own special needs!
- Helping/involving the sibling may indirectly help the entire family system!



Playing with Sibling

- **Problem:** Justin (age 6) cannot play with his sister Hailey (age 8). He hits her, grabs things from her, pulls her hair, etc.
- **Function(s):**
 - › Gain attention from Hailey
 - › Gain a desired toy
 - › Maintain control of the interaction



Robinson -Joy, Moskowitz, & Carr (in preparation)

Playing with Sibling: The Intervention

- 1) **Peer-Based Intervention with J's sister H**
 - a) **Psychoeducation:** Explain to H where J's behavior comes from
 - b) Teach H to praise appropriate behavior
 - c) Teach H to prompt use of functional communication
 - d) Teach H to reduce her reactions to inappropriate behavior
- 2) **Choice Board**
 - > Visual choice board of preferred activities
 - > H pick 4 activities & ask J which he wanted to play
- 3) **Incidental Play situations**
 - > Mom help H create situation in which H needed "help."
 - > Incidental prompts attempt to create initiation w/out direct prompt

PATERNAL
INVOLVEMENT

Personal Clinical Experiences with Fathers

- ⦿ Involved fathers
 - › Children display minimal problem behavior
 - › Focus on social skills
- ⦿ Uninvolved fathers
 - › Hinder treatment by being
 - Too permissive
 - Too punitive
 - Inconsistent
 - Argumentative
 - Disinterested/absent
 - › Stressed out mothers

Defining Father Involvement

- ⦿ Positive engagement activities
 - › 3 hrs / week
 - Wang and Bianchi 2009
 - › Up from .5 hrs / wk in 1965, 1.5 hrs / wk in 2000
 - Bianchi et al. 2006
- ⦿ Warmth and responsiveness
 - › Similar levels in mothers and fathers
 - › Father warmth is lower for older children
 - Lamb 2006

Definitions Ctd.

- Control
 - › Fathers report similar levels of efficacy
 - Hofferth 2003
- Indirect Care
 - › (e.g., selecting schools) – 34% fathers say mothers do it alone. 60% of mothers say they do it alone.
 - Hofferth 2003
- Process responsibility
 - › Fathers as primary caregivers, 17.2% overall
 - 20.5% of married, employed mothers
 - Lamb, 2010

Fathers in ASD

- **Mothers experience more daily hassles than fathers of children with ID.**
 - › (Gerstein et al., 2009)
- **Reduced play-time in ASD**
(Konstantareas & Homatidis, 1992)

Parent training = Mother training

- **Most parenting research is on mothers**
(Phares, Lopez, Fields, Kamboukos, & Duhig, 2005)
- **Clinicians work with mothers more than fathers**
(Duhig, Phares, & Birkeland, 2002)
- **Mother focus**
 - > Only mothers
 - > Mothers with some father assistance
 - > Mothers train fathers
(Binnendyk & Lucyshyn, 2009; Moes & Frea, 2002)
- **New studies target fathers**
 - > Demonstrating that fathers can learn too
(Elder et al., 2003; Elder, Valcante, Yarandi, White, & Elder, 2005; Seung et al., 2006; Winter, 2006)
 - > Identifying strategies to encourage father involvement
(Fabiano, 2007; Winter, 2006)

Theories on Why Fathers Are Uninvolved

- **Role specialization**
- **Mother is in charge**
- **Therapists discourage it**
- **Less reinforcing**

Fathers underserved

- Subjective reports:
 - > Uncomfortable with female dominated service systems
 - > Traditional parent roles discouraged direct father-child contact
 - > Inflexible meeting hours made it difficult for fathers to participate (Lillie, 1993).
 - > Fathers often considered an afterthought by professionals (Davis & May, 1991).

Why Fathers May be Important in Treatment of Children with ASD

- Father training has effectively been used to teach social skills in ASDs
- Knowledgeable: fathers may enhance assessment & treatment fidelity
- Fathers may relieve maternal stress & family stress by participating
- Unskilled fathers may hinder treatment
- Including fathers can help us assess & treat fathers' psychopathology and marital discord

MARITAL SATISFACTION

Marital Satisfaction

- Lower marital satisfaction in families of children with ASD than TD, ID, & ADHD (Abbeduto et al., 2004; Brobst et al., 2009).
- Stress and child problem behavior linked to lower marital satisfaction (Baker & Blacher, 2005).
- Lower levels of marital intimacy and intensity of love (Walsh & O'Leary, in preparation)

Mothers of Children with and without ASD and Marriages: A Comparison Study

- Purpose:
 - To compare mothers of children with ASD to mothers of TD children on marital satisfaction, intensity of love, general happiness, and daily stress.

Divorce

- Parents of children with autism have a higher divorce rate than TD families (Hartley et al., 2010). But there have been mixed findings.
- Risk of divorce remains high until child reaches adulthood.
- Single parent homes present added stress and decrease QOL.

Participants

- Two samples:
 - > 1) Sample of mothers of children with autism
 - > 2) Nationally representative sample of mothers of neurotypical children

Autism Sample

- N = 475 mothers (ages 20 – 71) who reported they had a child diagnosed on the autism spectrum
- Children were ages 3 – 41, 70% male, 30% female
 - > 58% diagnosed with autistic disorder
 - > 21% diagnosed with Asperger disorder
 - > 18% diagnosed with PDD-NOS
 - > 1% other

Nationally Representative Sample

- ⦿ N = 62 mothers (ages 20-65) of neurotypical children
- ⦿ Study goals: Assessment of prevalence and correlates of intense love.
- ⦿ Random digit dialing to married people across the 50 U.S. states.

O'Leary, Acevedo, Aron & Huddy, 2010

Measures/Procedure

- ⦿ Participants in both studies answered these questions:
 - How in love are you with your partner? (1 = Very intensely in love, 7 = Not at all in love).
 - How happy do you feel in your relationship with your partner? (1 = Perfectly happy, 7 = Not at all happy).
 - I am very happy with my life in general. Do you... (1 = Strongly agree, 4 = Disagree strongly).
 - I feel very stressed when dealing with my daily problems. Do you... (1 = Strongly agree, 4 = Disagree strongly).

Results

- Mothers of children with autism were:
 - › Significantly less intensely in love with their partner
 - $t(534) = 3.66, p < .05$
 - › Significantly less happy in their marriage
 - $t(534) = 5.74, p < .05$
 - › Significantly less happy with their life in general
 - $t(533) = 4.20, p < .05$

Results for Parents of Children with ASD

- Mothers were also more stressed than fathers $t(630) = 1.98, p < .01$.
- Married mothers and single/divorced mothers did not differ on daily stress, BUT single/divorced mothers were significantly less happy with their lives $t(584) = 2.94, p < .05$.

Discussion

- Parenting demands are high when there is a child with autism in the family.
- Mothers carry a larger portion of the burden of caring for the child. This might effect the marriage AND their general well-being.
- There is something to be said for resilience. Some marriages might be strengthened and having a partner might lead to better quality of life.

Having a child with autism = Doomed marriages?

- ⦿ The results seem to indicate this.
 - Mothers are less satisfied in their marriages, less happy with their lives, and less in love with their partner.
- ⦿ But...THERE IS A SILVER LINING!
- ⦿ Resilience factors and coping strategies.

Marriage & Family Literature

- Couples with children have lower marital satisfaction than couples without children (Twenge et al., 2003).
- Parents of TD children experience a higher risk of divorce during early childhood years too (Hartley et al., 2010).
- Parents of children with ASD have higher risk of divorce until child is an adult.

Resilience

- 73% of our ASD parent sample were married.
 - Some marriages might actually be strengthened by having a child with ASD.
- Might be moderated by having a healthy relationship before the child is born.
- Hartley's (2010) sample – 75% of the sample were married.
 - Most marriages can withstand the stress of having a child with ASD.

Limitations

- Data collected at a single time point.
- Marital satisfaction is not a judgment at one point in time, but a trajectory of marital evaluations over time (Bradbury et al., 2000).
- Need to examine these marital evaluations in mothers and fathers of children with ASD longitudinally.

Informing Research & Interventions

- Relationship problems and divorce can also influence the effectiveness of interventions.
- Interventions should address the complete family, not just the child with ASD.
 - › E.g. Marital therapy for discordant relationships, parenting skills, acceptance and coping techniques.

CONCLUSION: Tying it All Together

Informing Functional Assessment

- Conduct **comprehensive assessment** to evaluate which components are necessary and which family members need to be targeted
- **Assess mother and father** together during initial interview & observation in order to encourage early father participation
- **Direct observation** may be especially important (rather than solely relying on parent-report questionnaires or functional assessment interview) in cases where one or both parents are depressed

Informing Intervention

Flexible Multicomponent Approach

May need to include...

- Parent training for both mother & father
- Child training (i.e., teach replacement behaviors)
- Individual CBT for parents to address parental depression, anxiety, etc.
- Couples therapy to address marital discord
- Individual CBT for sibling
- Sibling as intervention agent
- Creating social support network for family members
- Acceptance-based approaches

Informing Research

- Compare joint parent training to individual parent training in families of children with ASD & DD
- Compare multi-component family intervention targeting parental psychopathology to standard PBS intervention targeting child only
- Compare multi-component family intervention targeting relationship distress in ASD & DD to standard PBS intervention
- Create empirically-based treatment programs for siblings of children with ASD
- Examine mediators & moderators (e.g., social support, coping style)
- Examine factors that influence more resilient coping strategies/parenting/marital relationships

Take-Home Message

- ⦿ Central IV in PBS is systems change
- ⦿ To fully be able to change the family system, we need to incorporate the knowledge base of other sciences and disciplines into the field of PBS
- ⦿ Unless we change the contexts and systems in which problem behaviors occur, even the most efficacious interventions might not be able to be maintained and sustained in the real world