

**PROMOTING RESILIENCE IN  
FAMILIES OF CHILDREN WITH  
AUTISM AND INSOMNIA  
THROUGH SOCIAL SUPPORT**

Cristy Roberts, RN PhD  
University of Missouri-Kansas City

# DISCLOSURES

**Cristine Roberts, RN PhD**

## **Learner Objectives**

**The learner will be able to describe how to design a mixed method study including integrating the analyses of the data from both methods.**

**The learner will be able to incorporate findings from this study into his/her practice or teaching that empower families to find internal and external sources that lead to resilience.**

**COI: there are no conflicts of interest**

**Employer: University of Missouri-Kansas City (UMKC) USA**

**Support through the UMKC research start-up funding**



# BACKGROUND

- Children with autism spectrum disorder (ASD) often have co-occurring disorders including sleep problems
  - Up to 80% of children with ASD
- Correlation between sleep disorders and challenging behaviors
  - Less sleep for whole family
- Sleep problems do not seem to go away without interventions
  - Behavioral interventions seem to work

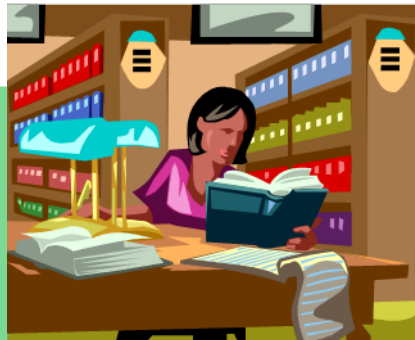


# RESEARCH QUESTIONS

## Quantitative:

**How does family resilience differ between families of children with ASD who have and do not have sleep problems?**

**Which independent variables among sleep problems, family resilience sub-indices, and family demographic data show the best prediction for positive adaptation?**



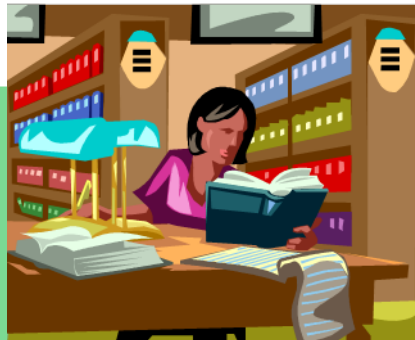
# RESEARCH QUESTIONS, CONTINUED

## Qualitative:

How are adaptation and resilience processes ameliorated by improvement of child's sleep?

## Mixed:

How do narrative findings of parents of children with co-occurring ASD and sleep problems support, expand, or conflict with the results of the regression analysis findings?



# DESIGN

An explanatory sequential mixed methods design involved :

**1) Collecting quantitative data first**

Survey data was used to analyze the variables of sleep problems and demographic data with family resilience

**2) Explaining those results with in-depth qualitative data**

Interviews with families whose children had sleep problems, family resilience was explored

Mixed design data was connected to analyze, compare, and contrast findings in order to establish relationships.

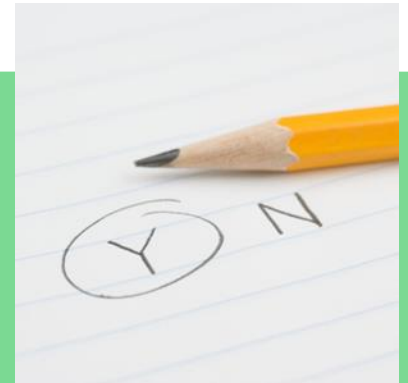


# METHODS

3 Questionnaires were mailed to parents of children with ASD with and without sleep problems

## 1) Demographic survey

child's gender, age, race/ethnicity, age of diagnosis, specific autism diagnosis, co-occurring diagnoses, food allergies, gastrointestinal problems, age of sleep problem onset, medications, therapies, those living in the home with ages, and who serves as the primary caregiver



# METHODS, CONTINUED

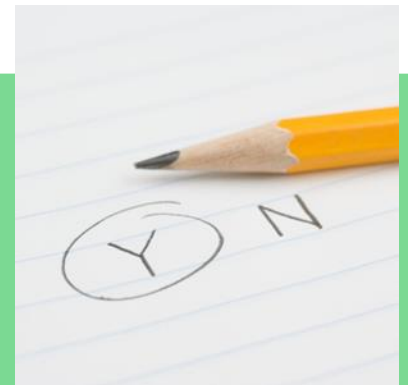
3 Questionnaires were mailed to parents of children with ASD with and without sleep problems

## 2) Family Index of Regenerativity and Adaptation-General (FIRA-G) (McCubbin)

family stressors, family strains, relative & friend support, social support, coping/coherence, family hardiness, family distress

## 3) Children's Sleep Habits Questionnaire (CSHQ) (Owens)

bedtime issues, sleep behaviors including amount of sleep (including parasomnias), night awakenings, morning waking, and daytime sleepiness





# PLAN FOR ANALYSIS

During interviews, family members were asked to describe the child's behaviors, family functioning, and any current sleep strategies.

Sequentially, retrospective evidence derived from parental responses to qualitative interviews described how families achieved positive or negative adaptation to discover richer insight into family processes.



# MIXED METHODS

- Not really two distinct kinds of data, but different ways to represent our experiences
- The quantitative results may indicate that deeper, richer data may be necessary

Verbal anchors on surveys may be interpreted differently by different participants

Might lose information in surveys because can't get at what the participant thinks (ideas can overlap)



# MIXED METHODS, CONTINUED

- Need the context
- Can elaborate, clarify, explain results
- Quantitative regression findings AND qualitative themes can support theory model

Why?

Answer the research question and get findings that lead to a second phase of research

(Sandelowski)



# RESULTS

75 families returned the questionnaires, 70 were complete

The survey data was analyzed through descriptive, correlation, analysis of variance, and regression statistics

6 interviews were conducted with 7 parents (regarding 8 children – 2 sets of siblings)

Interview transcripts were analyzed with thematic content analysis as well as analysis of the verbal responses related to sleep issues and adaptation



# DESCRIPTIVE RESULTS

All respondents were the **primary caretaker** of the child with ASD

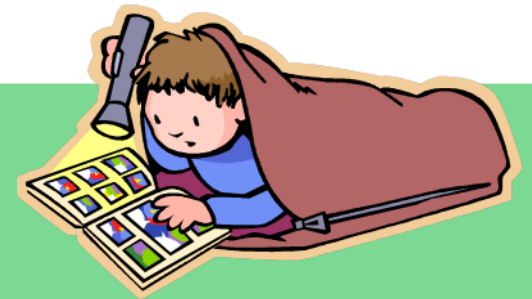
Almost all were **mothers** (n=69/98.6%) including one foster mother.

Average **age** of the child was 7.0 years

Most were **boys** (n=55/78.6%)

Most participants were **Caucasian** (n=61/87.1%)

The average **age at diagnosis** was 4.13 years



# DESCRIPTIVE RESULTS

Most children had sleep problems (n=56/80%) which began at an average of 2.6 years

Almost all of the children (n=68/97.1%) were involved in some kind of **therapy** such as physical, occupational, speech, or behavioral

Most children (n=52/74.3%) were taking **medication**, 43 of these children (61.43%) took either psychotropic medications or sleep medications.

6 (8.57%) responded that they could not meet their family's **financial** needs and 30 (42.86%) felt they could consistently meet them



# SURVEY RESULTS

Families of children who had sleep problems had lower overall resilience than families of children who did not have sleep problems (especially strains and distress; e.g. conflicts, finances, marital deterioration)

The child's age was not significantly related to any sleep or resilience scores

Time since the ASD diagnosis was not significantly related to resilience scores



# SURVEY RESULTS, CONTINUED

Families with financial problems had significantly lower coping-coherence scores when compared to families who did not have financial problems

Relative and friend support was significantly correlated with social support

Social support was significantly correlated with hardiness





# REGRESSION ANALYSIS

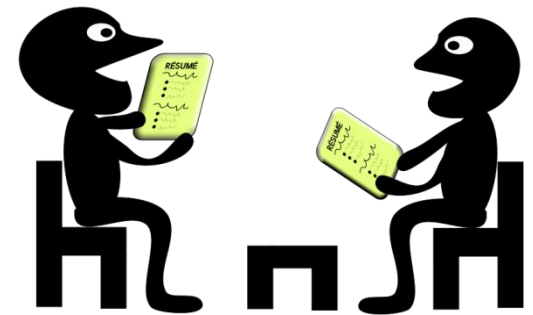
The significant predictors for hardiness are: less strains ( $\beta=-0.294$ ,  $SE=0.078$ ), social support ( $\beta=0.463$ ,  $SE=0.103$ ) and coping-coherence ( $\beta=0.726$ ,  $SE=0.283$ ). **Social support** contributes the most to the regression model with the largest beta estimate.

Social support is the “degree to which the family is integrated into the community, view the community as a source of support and feel like the community can provide emotional, esteem, and network support” (McCubbin, Thompson, McCubbin, 2001, p. 823)



# INTERVIEW DEMOGRAPHICS

- 6 sets of parents (7 interviewed – 6 mothers/1 father)
- 8 children (two sets of siblings)
- Age range – 5 to 13 years
- Gender – 5 boys, 1 girl
- Socioeconomic – range noted: one with nanny, one with homeless parent
- All have support services, some with ADHD
- All have sleep problems



# INTERVIEW RESULTS

## Child 's social issues

Behavioral issues: acceptable in young child – later not, bullying, can't leave teenagers alone at home, defiance, daycare was a “train wreck”, comply because of consequences, some aren't interested in others and some are forcefully physical, no spontaneous friends (e.g. in neighborhood), child with ASD determines play activity, odd speech, everything is extreme

## Other people's opinions

Developed sense of humor, “no one believed us”, isolation, friends suggest getting help, always apologizing, prepare for public exposure, see delays, others say they would “make him whatever”, rehearse public behavior “a hundred times”, allow others to have opinions and ignore



# INTERVIEW RESULTS, CONTINUED

## Procuring community services

Early intervention, delays in getting services, changes in service providers, nice to have guidelines, HCP often too quick to diagnose and don't live the problems, need to persevere, but diagnosis leads to services and support, services can't do it all but neither can parents

## Would appreciate improved sleep

Some never slept well, issues with noise and fears, couldn't self-soothe, need consistency, smooth transitions, preparing for sleep routine, out of bed at night and wandering in house, bedwetting, preparation for bed is exhausting, parents would like more freedom, child is awake during night and destroying the house, parents learn to "deal with it"



# INTERVIEW RESULTS

## Acceptance of child as is

“it’s called life”, “don’t want to cure my kid from being my kid”, “want them to go to college...and feel comfortable”, “all of a sudden, the light bulb came on”, “you love them with all your heart and you don’t give up”, see these behaviors in relatives, harder for husband, “never going to be like everyone else”, “can’t fully communicate with them”

## Adapt and improve over time

Adapted (denial → coping/acceptance), family communication is key, get help from relatives, sense of humor, “you can’t go in with the attitude of fixing it. There’s no fixing it”, sleep environment, some help from family, sleeping better over time



PERFECT

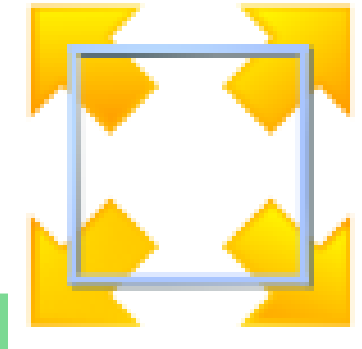
None of us are... And that's OK!

# MIXING: SUPPORT, EXPAND, OR CONFLICT?

Less sleep = more challenges, lower resilience scores  
(quant), harder for parents (qual) [support]

Socialization is one of the parents' concerns for their child  
(qual) [expand]

As children age, they may become more socially aware  
(qual) [expand]



# MIXING: SUPPORT, EXPAND, OR CONFLICT?

Meanwhile, social support can lead to family hardiness [a positive resilience index (quant)], help from HCW (qual) [support/expand]

Adaption over time (qual) & coping/coherence (quant) [expand/conflict?]

**In this case, the qualitative results expanded the quantitative results.**



# CONCLUSIONS

Higher hardiness scores for families of children with ASD who slept well indicate that families felt an increased inner-familial strength and consequently a higher sense of control in their lives.

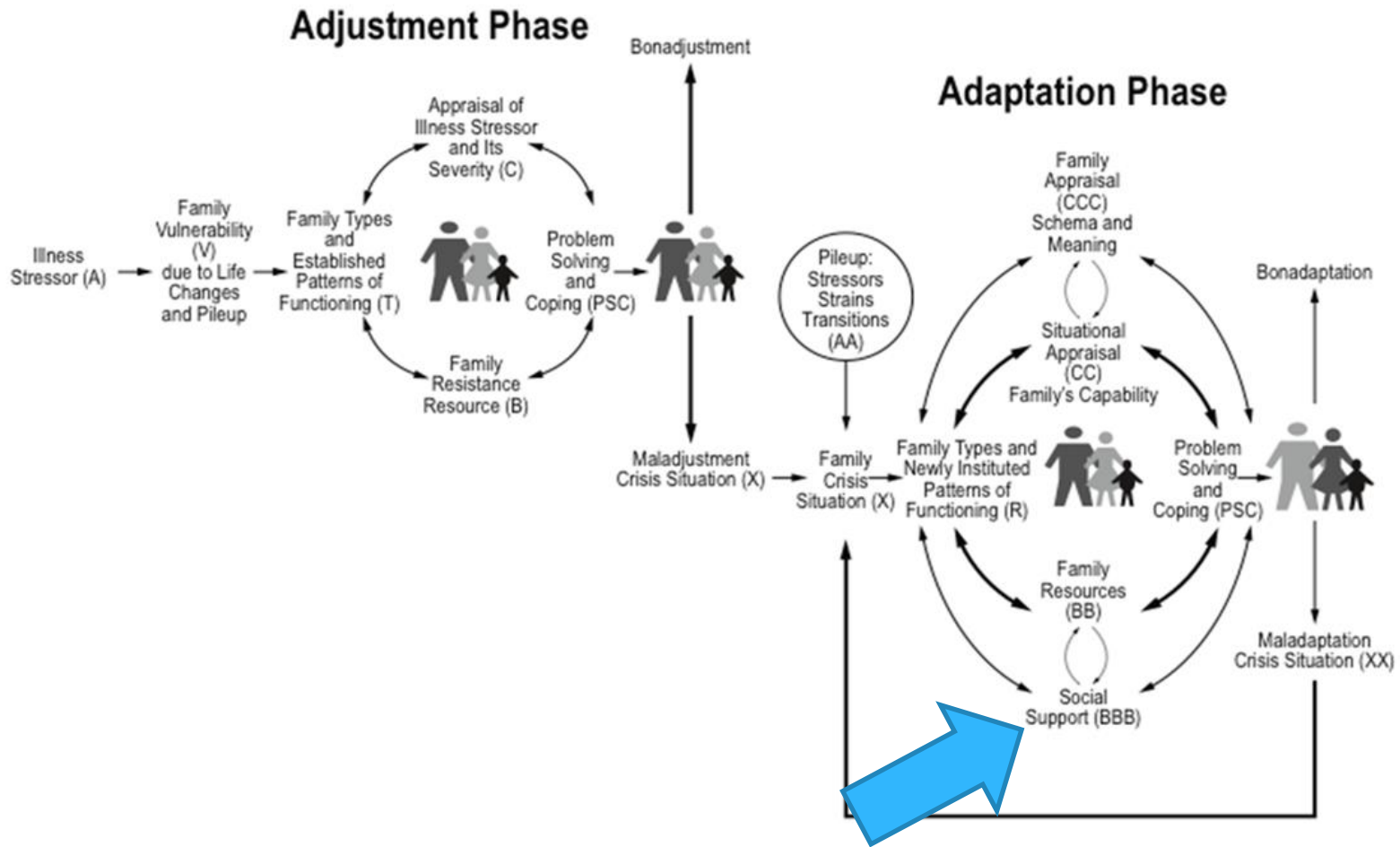
Hardiness refers to an active orientation to stressors and is revealed when families call upon their internal vitality.

Variables intrinsic to McCubbin & McCubbin's Family Resiliency model such as family's appraisals and capabilities, resources, and social supports can be used to help families of children with ASD and insomnia





# THE RESILIENCY MODEL OF FAMILY STRESS, ADJUSTMENT, AND ADAPTATION (McCUBBIN & McCUBBIN)



# DISCUSSION

Is it all about “social”?

In interviews, parents were concerned about child’s socialization

Can better sleep decrease impediments to socialization?

Social stories, social training (practice) works with some children to improve behavior and lead to better socialization.

Can social support (community) services from health care workers lead to better sleep which in turn can lead to higher family hardiness and less social isolation?



# LIMITATIONS

One geographic area

Bias may exist about “who” responded to requests to complete surveys and be interviewed

Incentive (gift card) may have influenced who responded

Participants may have answered in a manner that they expected the researcher would like



# NURSING IMPLICATIONS

Social support services for families need to provide assessments of family functioning, access to community services, and counseling including sleep hygiene strategies.

Ultimately, assisting families resolve sleep issues will help children with ASD integrate better into their community and social settings by ameliorating behaviors that may be exacerbated by sleep disruptions.



# REFERENCES

- Goldman, S. E., Richdale, A. L., Clemons, T., & Malow, B. A. (2012). Parental sleep concerns in autism spectrum disorders: Variations from childhood to adolescence. *Journal of Autism and Developmental Disorders, 42*(4), 531-538. doi: 10.1007/s10803-011-1270-5
- Hall, H. R. & Graff, J. C. (2011). The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing, 34*(1), 4-25. doi:0.3109/01460862.2011.555270
- Lutz, H. R., Patterson, B. J., & Klein, J. (2012). Coping with autism: A journey toward adaptation. *Journal of Pediatric Nursing, 27*, 206-213. doi: 10.1016/j.pedn.2011.03.013
- McCubbin, H. I, Thompson, M. I, & McCubbin, M. A. (2001). *Family Measures: Stress, Coping, Resiliency*. Honolulu: Kamehameha Schools.



# QUESTIONS?



*Thank you! Cristy Roberts*

**Acknowledgements:** An Lin Cheng, Biostatistician, UMKC  
Families of children with ASD who contributed to findings  
UMKC for providing start up funding