IMPLICATIONS FOR COOPERATIVE EXTENSION:

Families with a child who has chronic illness are vulnerable to potentially negative outcomes associated with psychosocial distress. The authors of this article review existing models of fostering child and parent psychosocial well-being, despite this risk. In addition, they developed and tested a model for addressing parental uncertainty and other risk with the goal of reducing parent distress. As parent distress decreased, child distress was expected to decrease.

Results of the study show that cognitive intervention to reduce parent uncertainty can help families manage the psychosocial burden of caring for a child with chronic illness. Areas for intervention follow.

- The nature of uncertainty and what it means for the parent and child.
- Learning and using effective communication skills.
- Ways to effectively think about and cope with challenges associated with the child illness.
- Effective problem solving strategies.
- The positive and negative aspects of social support and how to effectively use it.
- Integrating and applying the set of skills described above.

Overview:

This article provides an overview of the major resilience models in pediatric psychology and propose a new model developed by the authors to guide intervention. In addition, the authors report the results of intervention based on the new model and discuss implications for future research on families with children who have other chronic illnesses.

One major model of pediatric resilience is Wallander and Varni’s Disability-Stress-Coping Model which focuses on (a) biosocial risk (e.g., poverty, lack of social support) that the increase the potential for negative outcomes and (b) protective factors (e.g., family cohesion, adaptive coping styles) that support positive psychosocial adjustment.

Thompson and Gustafson’s Transactional Stress and Coping Model proposes child illness and treatment are a stressor to which families are challenged to adapt. Illness-related factors (e.g., disease type, diagnosis, severity), demographic variables (e.g., age, SES, gender), and intrapersonal processes (e.g., mutual influence between parents and the child) are all important to understanding adaptation.

Kazak et al.’s Social Ecological Model proposes many systems are involved in both child and parent adjustment to chronic illness. The child or parent is understood within the context of other ecosystems such as family, social group, school, community, and culture.

Each of these models is consistent with Bronfenbrenner’s ecological approach.
suggesting adaptation to chronic illness involves reciprocity between parents and children in broader contexts. Notably, research shows parent adjustment is one the greatest factors in child adjustment.

Building on these models, the authors developed the Parent Uncertainty Management Intervention Model (PUMI). In this model, three forms of parent uncertainty are considered: lack of information, ambiguity about the illness or through communication, and unpredictability may be present. In preparation for intervention for the parent and child, appraisals of child and parent risk are considered based on appraisals of parent uncertainty and the baseline psychosocial risk are considered. A core assumption is that parents and children risk is reciprocal, with each person’s risk influencing that of the other. The goal of the model is for parents and children to overcome the effects of risk, cope with difficulties, and avoid the potential negative pathway that can emerge through risk.

Method & Results:
A preliminary investigation of a 12 week interdisciplinary (psychology and nursing) intervention based on the PUMI model was conducted through a clinic. The intervention involved six skills-based modules Fifty-two mothers participated were randomly assigned to “treatment-as-usual” and the intervention.

The results showed the mothers participating in intervention reported each module in the intervention was highly satisfactory. Reductions in mothers’ distress related to decrease in child distress from pre- to post- treatment. Sufficient and acceptable results with the mothers rated “highly” in all the modules. Maternal distress reduced the child’s affecting symptoms throughout the intervention and treatment-as-usual groups. Mothers in the intervention group showed improvement on symptoms whereas many mothers in the treatment-as-usual group showed greater symptomology over time. Thus, the intervention was effective.

Conclusion:
The final concluding results of this article showed the value of targeting parent uncertainty for intervention. Future interventions to reduce distress in families of pediatric cancer patients are recommended that target parents and their cognitive appraisal processes to address illness uncertainty, and the use of an interdisciplinary team. Specific stressors associated with the chronic illness can be identified and addressed, in part, through intervention addressing parent uncertainty.