

Family Dynamics
and Difficult
Moments: A
Different Facet
of Rare Diseases

Eric Scott, Ph.D.

Clinical Associate Professor of Pediatrics and
Anesthesiology

Director, MiPAIN

Disclosures

- Partial funding from NIH
1R01DA052310-01A1

Objectives

- Share stories of common family dynamics that we have encountered while working with families
- Share several models of how stress and illness can combine to form challenging family dynamics
- Propose several treatment approaches that can help enhance coping strategies and reverse problematic family dynamics

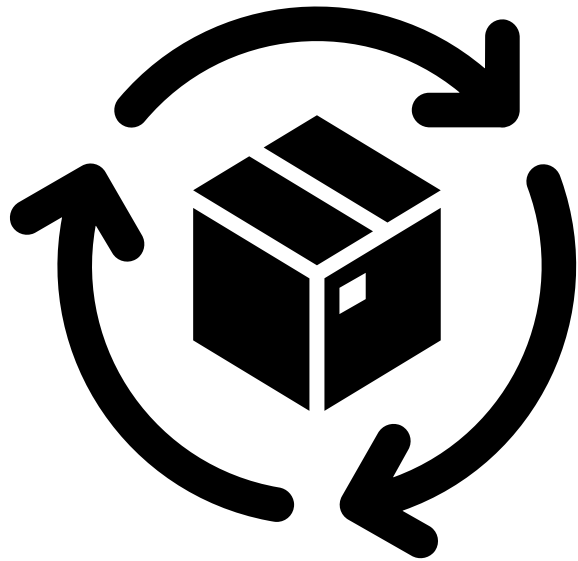


Family

Group of individuals related by blood or marriage/partnership

Dynamic


the forces or properties which stimulate growth, development, or change within a system or process.



Family Dynamics

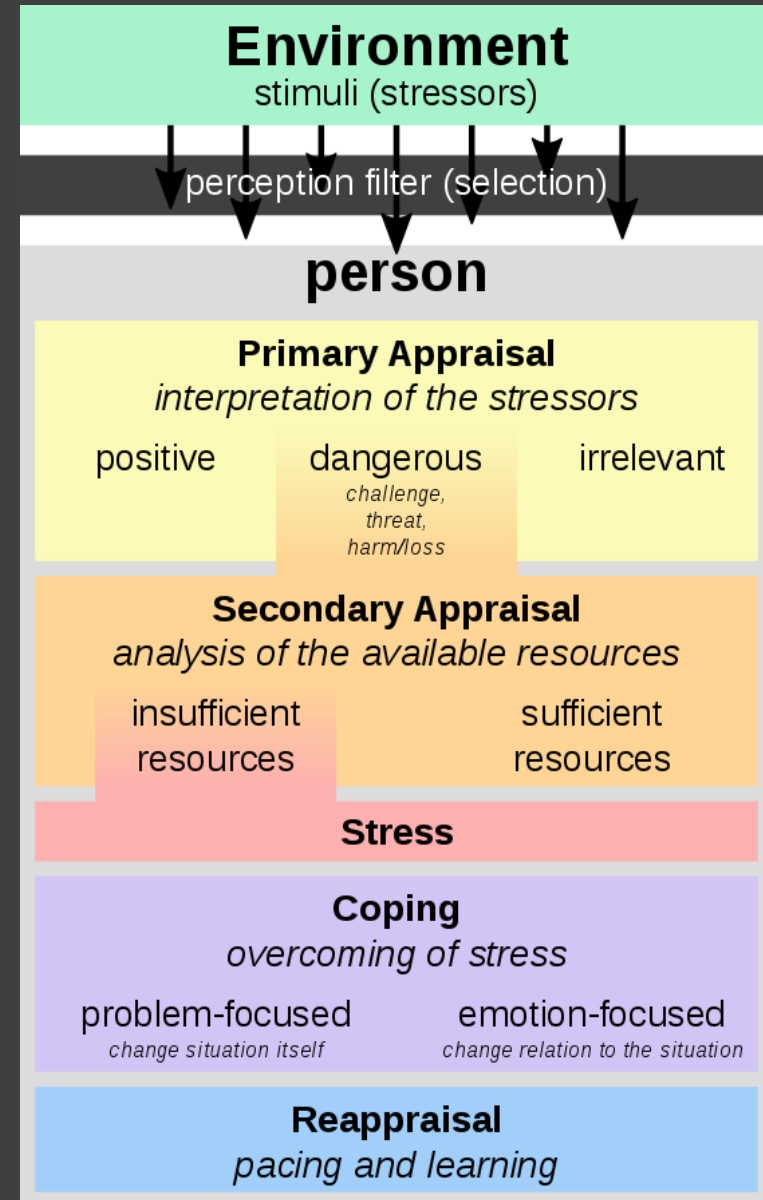
- Series of behaviors or patterns that may have preceded and/or evolved around the patient's symptoms, and may impede patient independence and optimal functioning during treatment



An aerial photograph of a winding asphalt road on a steep, grassy mountain slope. The road curves in a series of S-shapes, with stone retaining walls on the outer edges of the turns. The sun is low in the sky, creating long shadows and a warm, golden light. The terrain is rugged and covered in green vegetation.

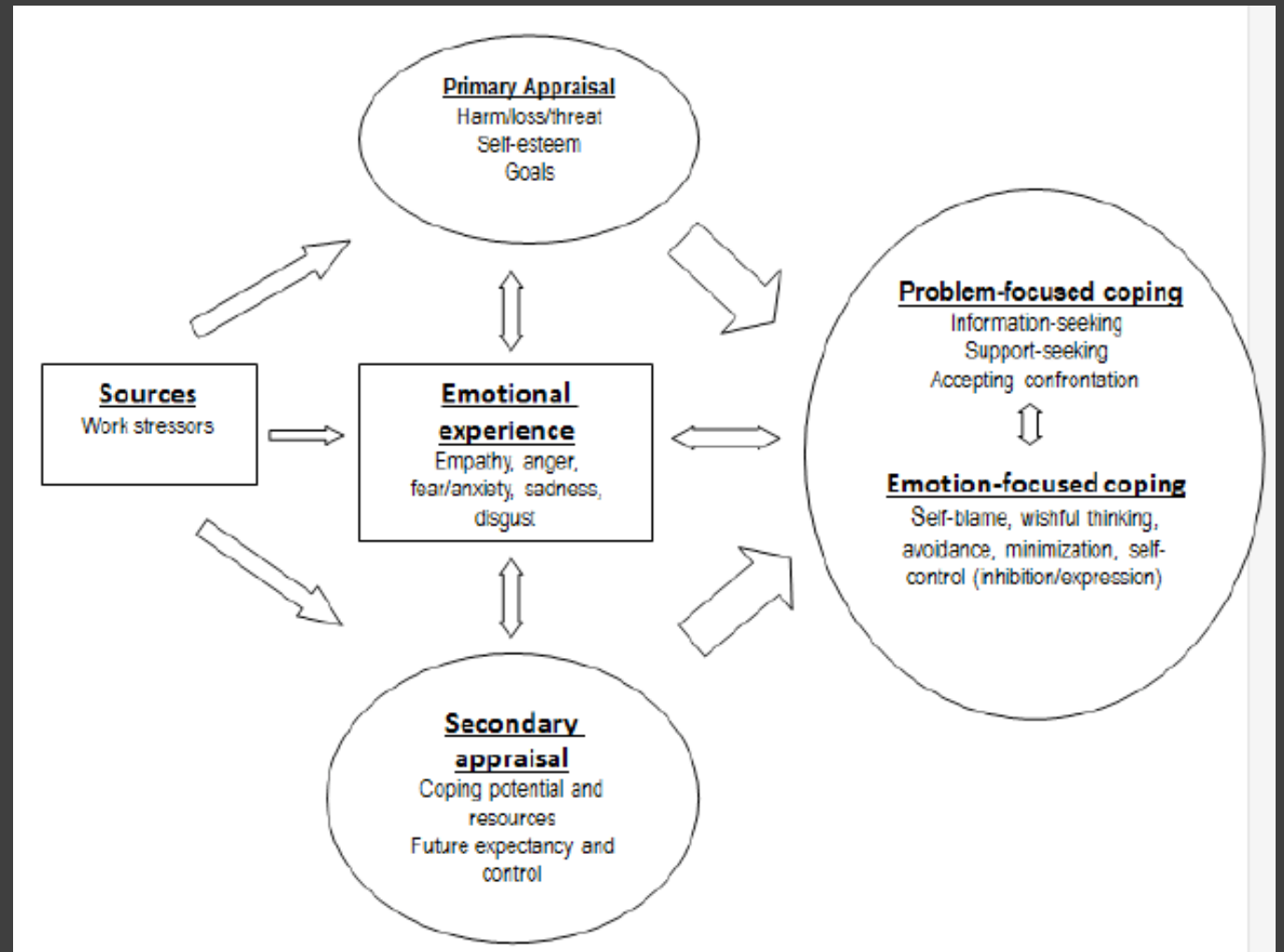
Rare diseases
often create
interesting
pathways

Transactional Stress and Coping Model (Lazarus)



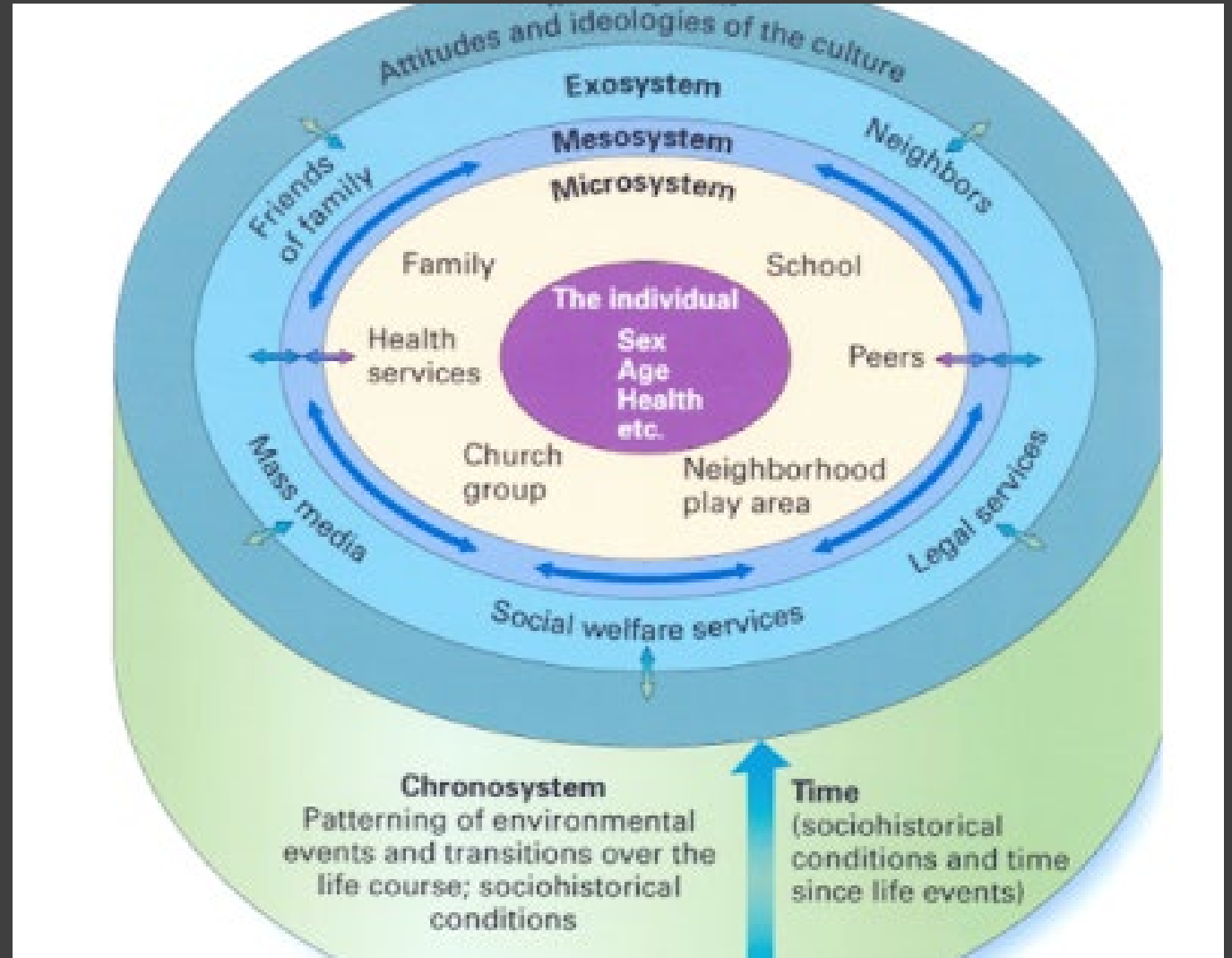
Folkman Model of Stress and Coping


Combined with previous
Lazarus model, you will often
see Folkman and Lazarus
paired together



Ecological Model

Bronfenbrenner

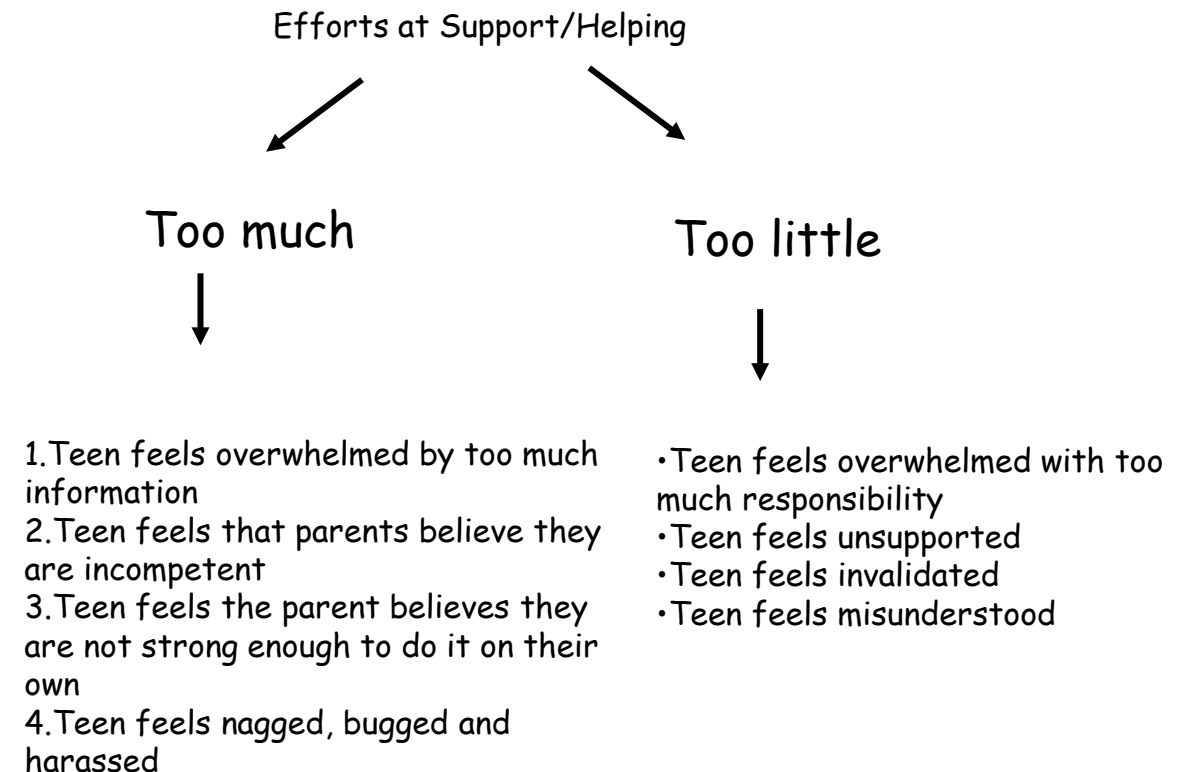


An aerial photograph of a winding asphalt road in a mountainous, green landscape. The road curves through the hills, creating a series of loops and turns. The terrain is covered in dense green vegetation, and the overall scene is captured in a slightly dim, natural light. A vertical white line is positioned to the right of the text.

Diseases often
create
interesting
pathways

Common Family Dynamics

- **Misguided support** – In their efforts to support the patient, family members may engage in behaviors that undermine the teen’s confidence and sense of independence. This may involve either lowering expectations or applying excessive pressure for rapid change and improvement in function.



Additional Dynamics

- **Overprotection** – This reflects the tendency of family to restrict the patient's activities in the service of recovery, which may in fact reinforce inactivity and contribute to deconditioning.

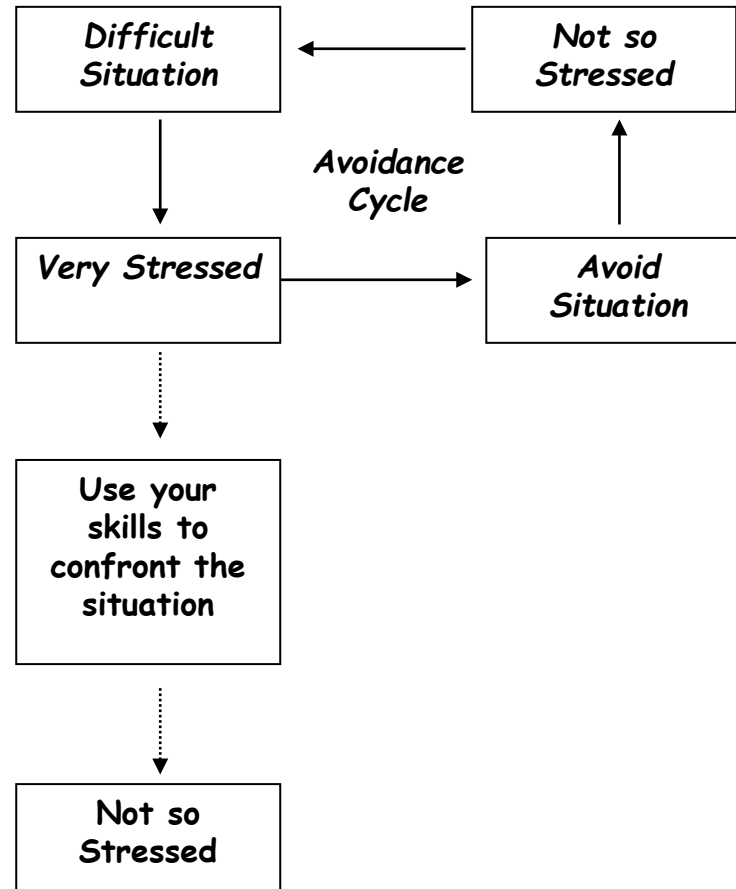
Communication pattern – Family communication patterns may involve poor conflict resolution, difficulty communicating affect and avoidance of discussing emotionally charged issues.

- **Attributions** – Patient and family may tend to attribute both illness and recovery to factors outside themselves and often beyond their control (i.e., External Locus of Control).

- **Patient independence in managing illness** – Patient self-confidence is often undermined via immersion in the ill role, whereby family members increasingly take over their responsibilities and provide assistance that may not necessarily be needed (closely related to Overprotection and Misguided Support).

- **Social/peer dynamics** – Patients with chronic, complex medical conditions can become anxious and avoidant of normal peer situations after long periods of isolation away from school and social events.

Understanding the avoidance Cycle



Children's Health and Illness Recovery Program

Multifaceted approach with emphasis on
rehabilitation

Elements taught in CHIRP

- Education about disease
- CBT
- Relaxation: biofeedback and
hypnosis
- Pacing
- Cognitive restructuring
- Sleep hygiene
- Problem-solving
- Assertiveness/communication
skills



Patient & Family Workbook

Why CBT works



MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

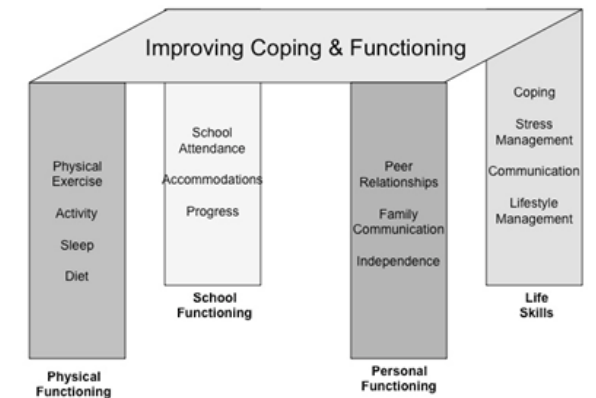
- CBT aims to use skills to modify situational, emotional, familial, and behavioral factors that play a role in disease and related consequences
 - Helps children and adolescents adhere to tx recommendations
 - Engenders positive coping skills
 - Reduces physiological and psychological stress
 - Addresses family factors
 - Empowers patients through expectations



MICHIGAN MEDICINE

UNIVERSITY OF MICHIGAN

- Overall goal of CHIRP and other rehabilitative approaches is to teach skills that can be directly applied to either solving a known problem OR
- Helping individuals deal more effectively with the distress and outcomes of uncontrollable disease, symptoms or consequences of treatment



Summary

- Stress and coping models can help us understand how and why specific family dynamics may arise
- Not all dynamics are harmful, but with examination, we can learn to help those with illness/disease acquire and use skills to cope as effectively as possible
- Avoiding the avoidance cycle is possible by using approach coping skills to reduce the impact stressful situations have in our lives
- If you have questions, please reach out at erlscott@med.umich.edu