Pediatric Treatment Adherence

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Definition

The failure to follow through on prescribed medical treatments such as

medications,
lifestyle and behavior changes (e.g, specific diet or exercise recommendations),
laboratory monitoring,
referrals to specialists
and adhering to primary preventive practices like vaccinations

is a common reason for psychiatric consultation in the pediatric setting.


How much common?

Nonadherence in Adult Populations

- One study showed adherence rates of approximately 50% for acute, short-term antibiotic administration in the treatment of respiratory tract infections.

Adherence rates in pediatric medical care for both acute and chronic illnesses are lower compared to adults.

Non-adherence in Pediatric Chronic Illnesses

- Primary care and behavioral health providers, as well as other specialists working with child and adolescent populations deals with adherence problem in chronic pediatric illnesses including asthma, diabetes, juvenile rheumatoid arthritis (JRA), cystic fibrosis (CF), seizure disorders, obesity, solid organ transplants, bone marrow transplants, cardiac malformations, cerebral palsy (CP), human immunodeficiency virus (HIV), and congenital genetic and developmental disorders.

Nonadherence in Pediatric Populations

- Problems with treatment adherence frequently arise in adolescents who have chronic illnesses such as diabetes mellitus or in organ transplant recipients who may have complex medication regimens or stringent requirements for medical monitoring or dietary restrictions.

Nonadherence in Pediatric Populations

- Ettenger et al. found that two-thirds of adolescent renal transplant recipients failed to adhere to their immunosuppressant medications.
- Within this group, 15% experienced graft rejection
- and 26% had graft dysfunction.

Overreporting

- A recent study by Bhatia et al. (2017) revealed that adherence rates for a 2-year course of once-daily 6-mercaptopurine (6MP) are over-reported in ALL patients enrolled in their study.
- For effective treatment, 95% of doses must be taken. The study used patient and parent self-questionnaires and employed electronic microchips on pill bottles for correlation between questionnaires and actual dose-taking.

Overreporting

- They found that up to 84% of patients were over-reporting their medication compliance on self-reports, with 23.6% of the patients who were over-reporting medication doses taken having the highest noncompliance rates in the study.
- This finding is concerning due to risk of relapse and highlights the need for oncologists and pediatricians to actively monitor treatment adherence with measures other than self-report.

Medical Outcomes

- Studies have shown a direct relationship between nonadherence and morbidity and mortality in several chronic illnesses, including asthma and diabetes.
- Nonadherence in patients with infectious diseases such as tuberculosis or HIV is related to increased morbidity and to the emergence of drug-resistant infectious organisms.

Medical Outcomes

- Finally, nonadherence can interfere with medical treatment decisions by leading physicians to misattribute treatment failures to ineffective treatment agents or by exposing patients to unnecessary diagnostic procedures.

Medical Outcomes

- Nonadherence may lead to medication dose escalations or switching medications especially when nonadherence is not identified and mislabeled a medication failure.
- These changes can lead to worsened outcomes, as the patient may be inadvertently given a higher dose than needed with resultant side effects, as well as higher resource utilization.

Quality-of-Life Outcomes

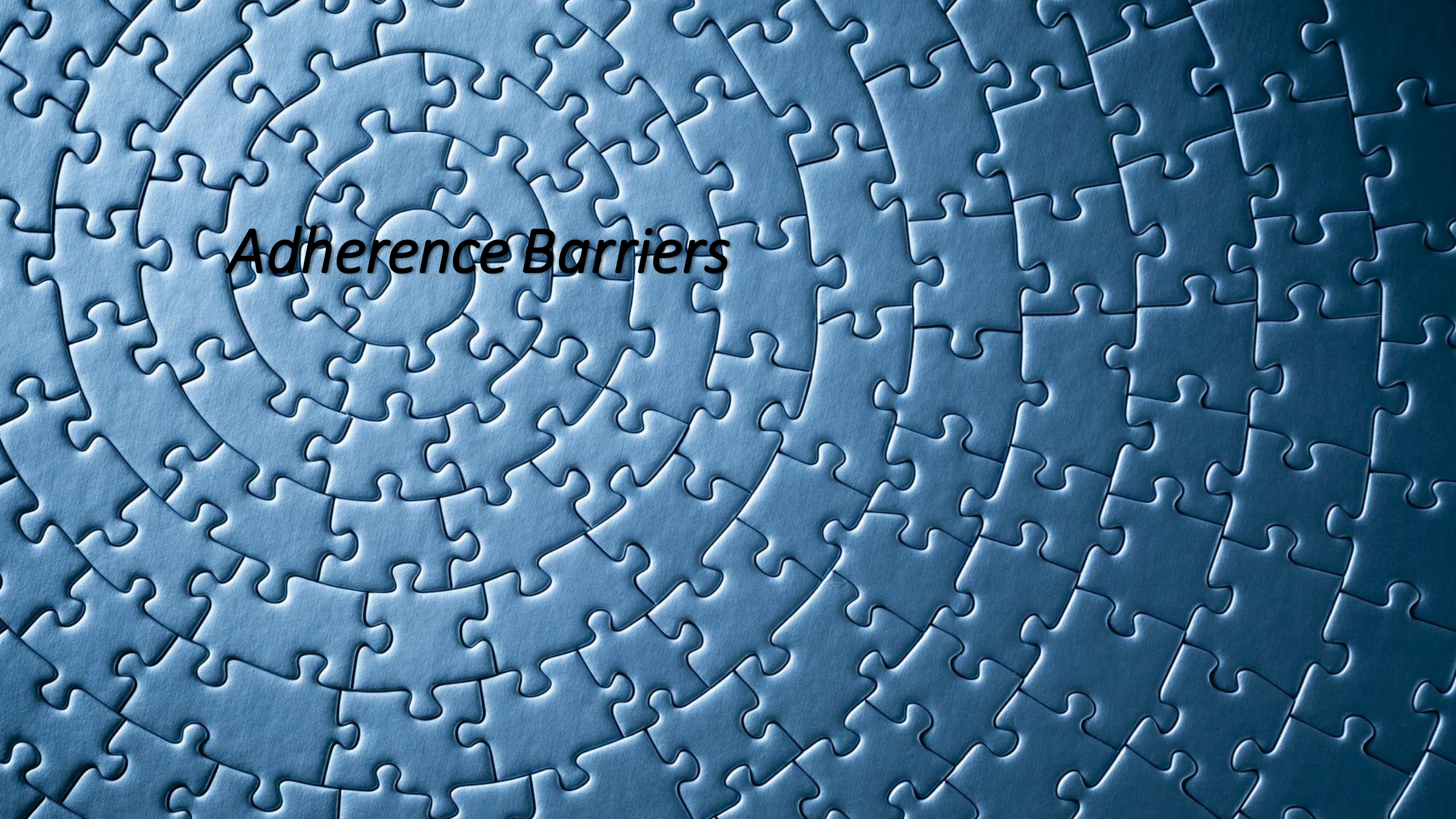
- Nonadherence affects the quality of life of both the child and other family members.
- The medical consequences of nonadherence can lead to decreased physical ability to participate in recreational and social activities.
- Children hospitalized for medical complications of nonadherence experience other negative consequences such as missing school, which frequently leads to lower academic performance.

Financial Outcomes

- The increased morbidity associated with nonadherence has been related to higher health care costs due to unnecessary or extended hospital admissions.
- Nonadherence can also burden family members who must miss work or incur childcare and transportation expenses.

Financial Outcomes

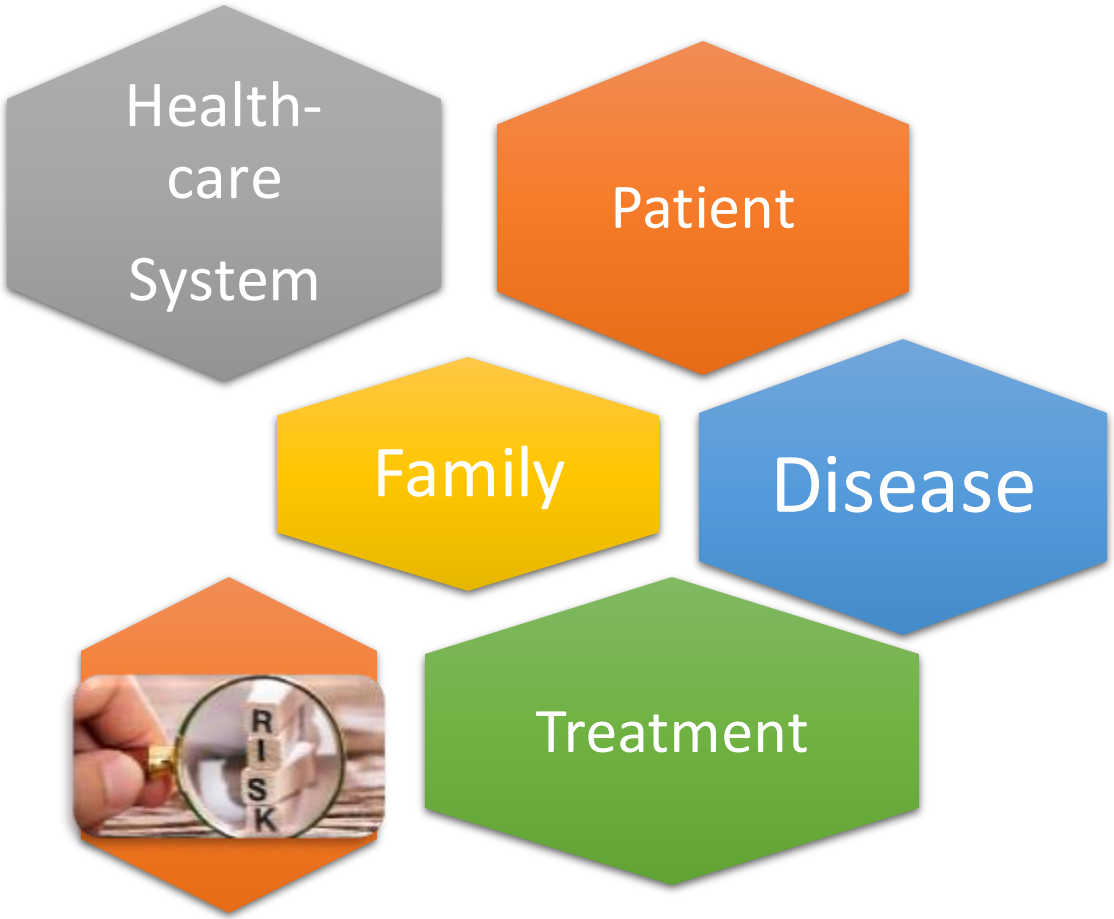
- Overall, poor adherence to treatment regimens is estimated to result in $100–$300 billion in health care in the United States annually


Adherence Barriers

Case vignette

- *Emma is a 13-year-old female with Type 1 diabetes mellitus (T1DM) diagnosed at age 6 and a recent hospitalization for diabetic ketoacidosis last month.*
- *Her most recent hemoglobin A1C level of 11 is elevated.*
- *You were asked to consult for concern of possible depression and treatment adherence issues impacting her diabetes care.*

Risk factors associated with treatment nonadherence in children and adolescents



Patient Correlates

- Presence of denial regarding illness
- Lack of knowledge about disease/perceptions of disease severity
- Feelings of pessimism regarding illness
- Adolescence
- History of behavioral difficulties
- Past emotional difficulties
- Low self-esteem

Family Correlates

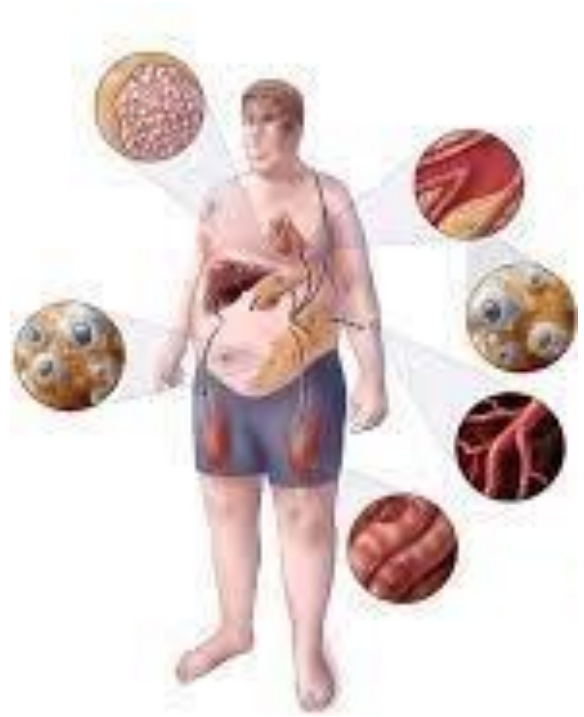
- Lack of parental supervision
- Single-parent family
- Parental conflict
- Parental psychopathology
- Child abuse and neglect
- Poor family support
- Low socioeconomic status
- Lack of family cohesion
- Poor pattern of family communication

Family Environment

- Family environments characterized by firm guidance, clearly stated rules, frequent parental expressions of and acceptance tend to have children who internalize positive and healthy personal values.

Disease Correlates

- type of illness
- its symptom severity
- Long duration of illness
- Few or no symptoms

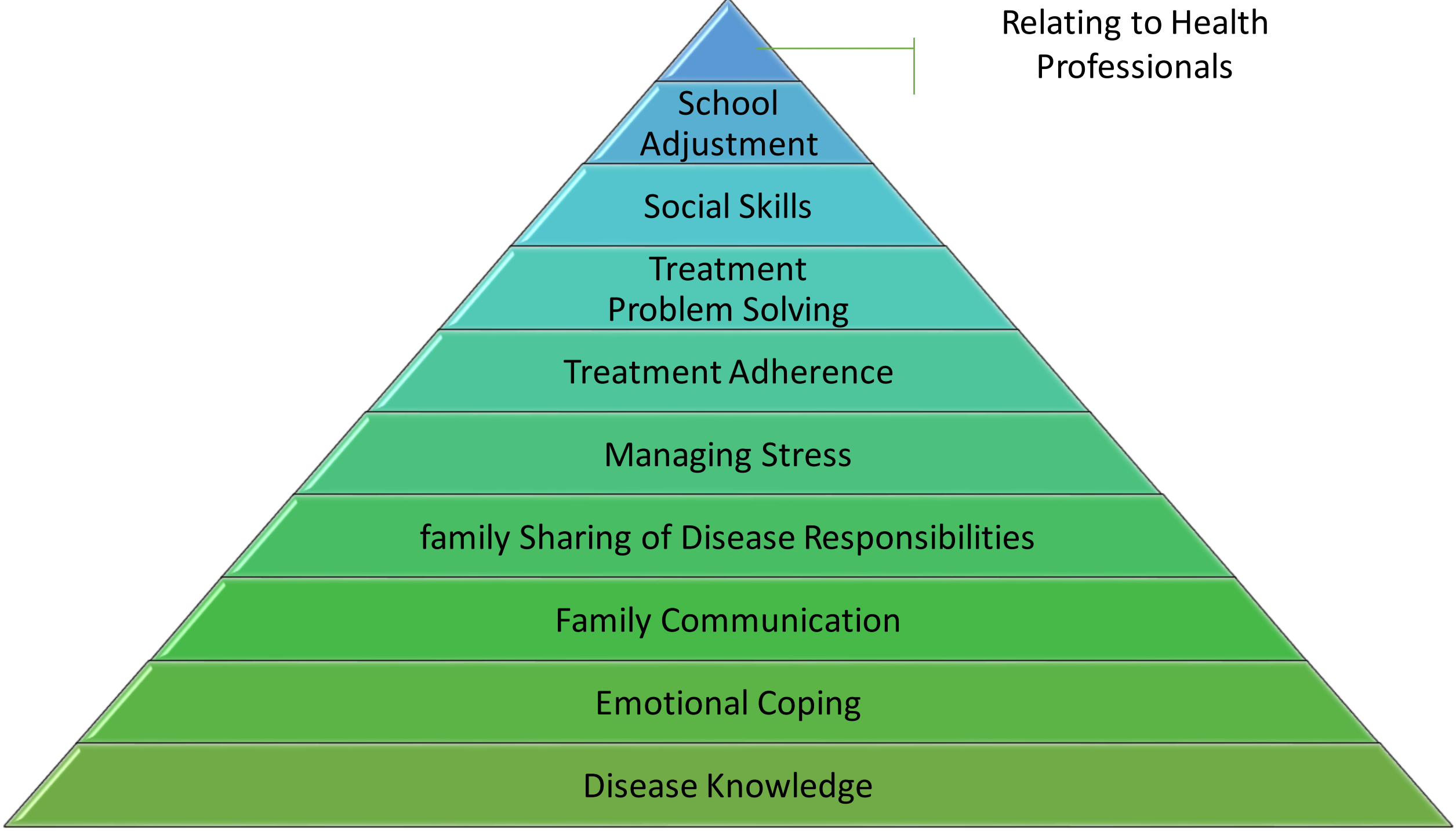


Treatment Correlates

- Complexity of the treatment regimen
- Invasiveness (difficulty of medication administration),
- Lifestyle changes including diet, exercise, and activity restrictions or modifications
- Effectiveness of treatment
- Unpleasant medication side effects
- Low level of perceived efficacy of treatment
- High financial costs

Healthcare systems Correlates

- Ease of enrolling in insurance coverage,
- Partnership with patients and providers
- Availability of other programs that might help with patient reminders or other system issues involved in adherence.


Relating to Health Professionals
School Adjustment
Social Skills
Treatment Problem Solving
Treatment Adherence
Managing Stress
family Sharing of Disease Responsibilities
Family Communication
Emotional Coping
Disease Knowledge


ASSESSMENT
CHECK
EVALUATE

Patient's understanding of illness and treatment

Describe the patient's understanding of the illness and treatment regimen, including the following:

1. Understanding of illness
2. Understanding of treatment regimen
3. Understanding of consequences of nonadherence

1. Where are medications kept?
2. Who is responsible for remembering the treatment?
3. What is the degree of family supervision of the treatment?
4. What aids are used to facilitate treatment?
5. What are the patient's responses to missed treatment?

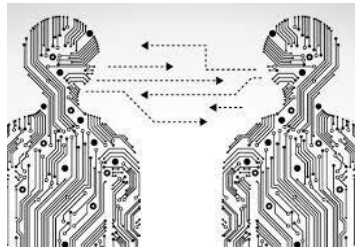
Treatment protocol

Degree of family supervision of the treatment

- Direct observation of treatment
- Parent dispenses or administers treatment
- Calls to remind patient
- Absence of supervision

- Medication dispensers or pillboxes
- Pagers or alarm clocks
- Telephone calls
- Signs posted around house

Aids are used to facilitate treatment



Pattern of adherence

- Describe the pattern of missed treatments, including the following:
- 1. Frequency of missed treatment (e.g., once a day, once a week)
- 2. Days, times, and places of most frequently missed treatments (e.g., school days, weekends, mornings, evenings, home, school)
- 3. Circumstances associated with missed treatments (e.g., with one parent and not the other in separated families, while one parent is away or out of town, when one parent is working longer hours, school vacations, sleepovers)
- 4. Patient's level of distress associated with missed treatments

Case Vignette

- *Emma lives at home with both her parents. She explains she is struggling with her 8th grade coursework and "feels stupid" since she is in danger of failing this year.*
- *She is tearful, recently having superficially scratched her wrists after an argument with her parents. She denied any suicidality, but sometimes feels she does not have a good reason to be alive.*
- *She reports that for several weeks to months, she rarely checks her finger-stick glucose level at school and only occasionally at home.*

Case Vignette

- Prior to the start of the school year, she was able to independently manage her diabetes, with her parents needing to supervise her only on rare occasions.
- Since summertime, her parents noted she was more withdrawn or angry at home, and they had more difficulty communicating with her.
- This change coincided with the family moving neighborhoods and schools and complaints that she did not have any friends at her new school.

Treatment approaches for pediatric treatment adherence

- The family should be the primary focus of interventions designed to improve adherence to therapeutic regimens in pediatric populations.
- Multicomponent interventions including *education, parental involvement, self-monitoring, reinforcement, and problem-solving* have been most successful in promoting adherence to chronic regimens

Treatment approaches for pediatric treatment adherence

Educational Interventions

Educational Interventions

- Written and verbal educational interventions should be part of the routine care provided when patients are *first* diagnosed or when there is a simple goal, such as helping *adolescents* take on increased responsibility.
- Consultants must assess the knowledge of the patient and family regarding the illness and its treatment before initiating any adherence-enhancing program.

Educational Interventions

- It is important to review with the family the ***common principles of adolescent development*** and how they relate to treatment adherence.
- This assessment should emphasize the family's role in supporting their child's treatment by providing adequate supervision and should help the family ***anticipate difficulties*** that may interfere with adherence.
- The family should also receive guidance on how to ***respond to nonadherence***.
- Families often react in an overly strong and punitive manner and withdraw privileges rather than increasing levels of supervision until such time that the adolescent demonstrates greater ability to take responsibility for the treatment.

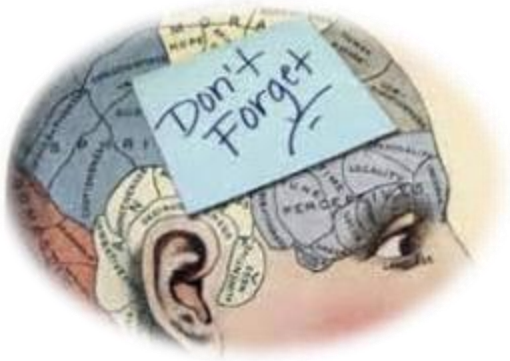
Organizational Interventions

- Simplification of the Medical Regimen
- Memory Aids
- Enhanced Supervision

Simplification of the Medical Regimen

- It is always important to simplify the treatment regimen wherever possible.
- Patients with chronic illnesses may be seen by several specialists, each of whom may be prescribing medications without awareness of the total burden of the treatment on the individual.

Memory Aids



Memory Aids

Helpful strategies to remind patients about their treatments include

- Use of pagers,
- Alarm clocks,
- Telephone calls or text messages from parents or pediatric clinics
- Using Pillboxes,
- Storing medications in highly visible places,
- and posting reminders around the house.

Enhanced Supervision

The first step in treating nonadherence is to increase the level of supervision. This increase may involve

- Parental observation or administration of treatments,
- More frequent clinic visits,
- Or laboratory monitoring.

Behavioral Interventions

Behavioral Interventions

- Data support the conclusion that interventions that integrate behavioral approaches including the use of incentives are more effective than programs based on educational and organizational approaches alone.
- To implement these strategies, families need to understand the importance of reinforcing desired behaviors by providing incentives rather than focusing on negative behaviors.

Behavioral Interventions

- Specific behavioral plans with appropriate incentives and an effective system of monitoring and rewards should be tailored for each patient.
- For younger children, the program may involve a sticker chart tied to age-appropriate incentives.
- For adolescents, adherence may be tracked using signatures on a chart with a similar system of short- and longer-term incentives.

Psychotherapy

Psychotherapy Interventions

- In situations in which psychiatric comorbidity has been identified, the patient and family may be referred for psychotherapy.
- Treatment may involve both individual and family therapy,

Psychotherapy Interventions

- Referrals for family therapy are specifically indicated for families who are unable to provide adequate supervision despite clear education about its importance.
- Family therapy may also be indicated when significant family conflict leaves the parents unable to coordinate their treatment efforts and motivates the child to act out family conflicts in the form of nonadherent behavior.