International Nurse Specialist Group/CF (INSG/CF)

Implications of cystic fibrosis on adolescents and their families

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ADOLESCENTS

"*lacking in sexual self-restraint, fickle in their desires, passionate and impulsive (…) ability to choose (…) self-determination (…) egocentrism* ".

(….) time for independence, identity, and career choice - importance of increased self-determination in adolescence.

Aristotle 4ºB.C./ (1941 translation)

"*A change in humor, frequent anger, a mind in constant agitation, makes the child almost unmanageable. His feverishness turns him into a lion. He disregards his guide; he no longer wishes to be governed*. **Rousseau,** 1712-1778

ADOLESCENCE

- Somewhat tumultuous and demanding time for the teenager and their family. (parents are often in middle age crisis)
- (…) great changes in all domains of life, including physical, biological, cognitive, developmental, and social,
- (…) as well as the transition from being a dependent child to an independent adult.
- (…) adolescence is a time when teenagers are acutely focused on their appearance, body image, conforming, and comparing themselves to their peers.
- (…) self-worth and body image is strongly tied to how well they conform. Any differences from peers can be particularly distressing

ADOLESCENCE

- **PHYSIOLOGICAL** :The pituitary gland releases higher levels of follicle stimulating hormone (FSH) and luteinizing hormone (LH) that activate the sex organs which in turn produce their own hormones.

- **COGNITIVE** : Formal Operational Stage : logical thinking, deductive reasoning, and systematic planning; skills *(i)* to consider possible outcomes and consequences of actions *(ii)* to envisage alternatives to solve problems *(iii)* to anticipate and plan actions. (Piaget, 1972)

ADOLESCENCE

- Adolescence is a veryyyyyyyy lonnnnnnnnggg transitional stage.

  - Not just in years but in changes-.

- Individual characteristics must be considered (e.g intellectual capacities; cognitive experiences)

- Adolescent egocentrism is developmentally normal; cognitive limitations should be expected (*e.g.* (less)logical thinking in issues that respect themselves)

CF - CHRONIC LIFE THREATNING DISEASE

How am I suppose to relax ? I know my child is only 11 but if you think about how long she is expected to live… she is already old ! She is older than me ! *Mother of child with FQ*

SOME STRESSORS ARE EXPECTED

eating systemic and progressive

COPING IS DEMANDED

Although recent st showe
are able to adapt a achieve their developmental
some emotional a behavioral disturbance is fre

IMPLICATIONS

IMPLICATIONS EFFECTIVENESS

ADOLESCENCE CF

BIOLOGICAL

Many CF health-related problems become more "visible" during the adolescent years

- ❖ Delayed puberty
- ❖ Infertility (boys)
  dysfu
  vesicl
  ejacu
- ❖ Shor
- ❖ Redu
- ❖ Unde
  catab
  absorption and eating behavior
- ❖ Increased insulin resistance that may cause diabetes/worsen diabetic control

PSYCHOLOGICAL
Demands

UST AND ACCEPT
SIOLOGICAL CHANGES

PRIVACY;
ICE

IEW AND
TIONS

"Don´t waste my time. Adolescence will probably be the larger portion of my life. I must live it"
- 16 years old boy years complaining about his daily waiting time for cinesiotherapy

IMPLICATIONS OF CF ON ADOLESCENTS AND THEIR FAMILIES

Where do implications come from?

DETERMINANTS

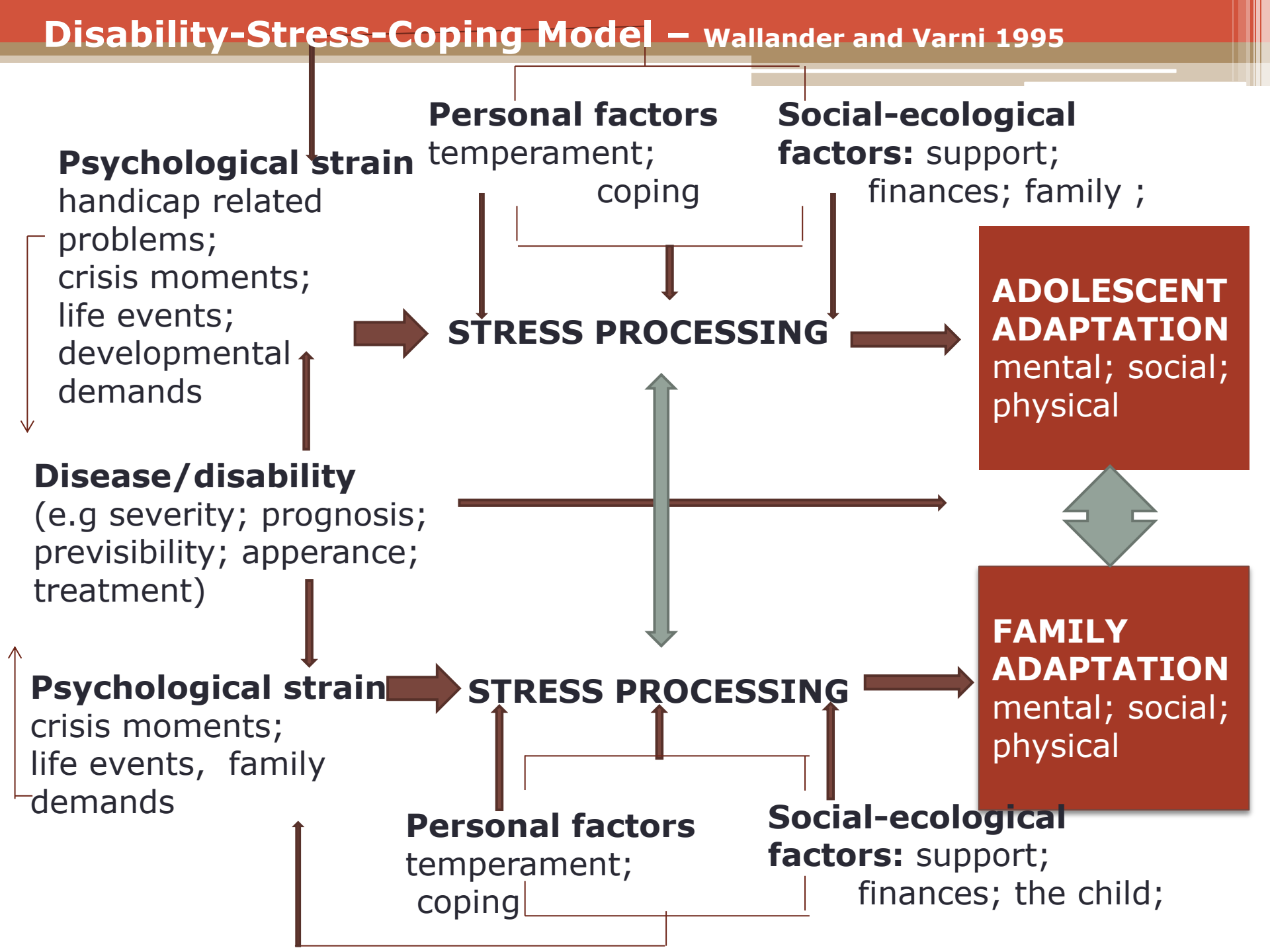
Identify and relate them

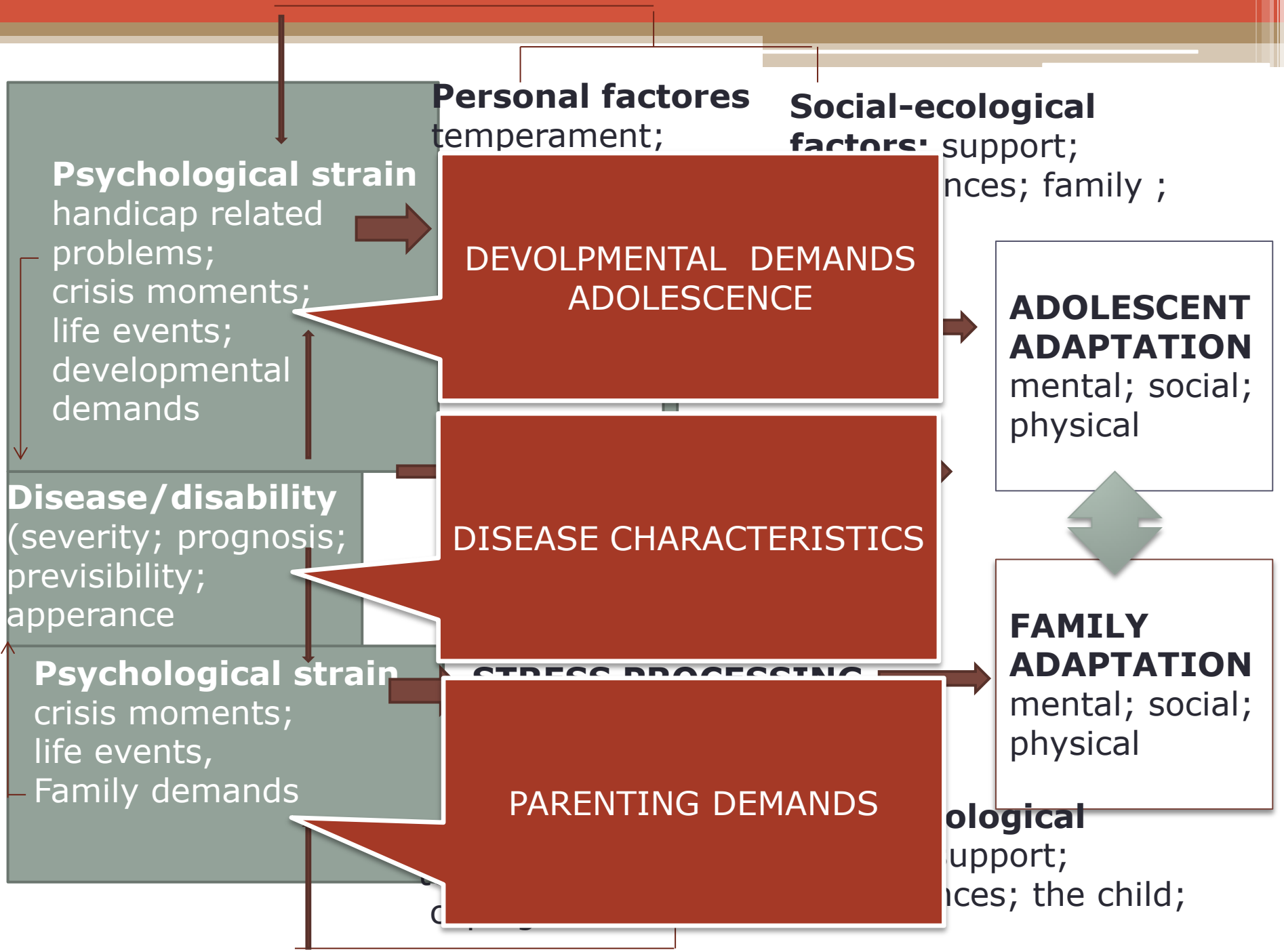
MAKING SENSE

Prevent their effectiveness

WHAT TO DO AND HOW TO DO IT

Disability-Stress-Coping Model – Wallander and Varni 1995




Personal factores
temperament;
Social-ecological
factors: support;
nces; family ;
Psychological strain
handicap related
problems;
crisis moments;
life events;
developmental
demands
DEVOLPMENTAL DEMANDS
ADOLESCENCE
ADOLESCENT
ADAPTATION
mental; social;
physical
Disease/disability
(severity; prognosis;
previsibility;
apperance
DISEASE CHARACTERISTICS
FAMILY
ADAPTATION
mental; social;
physical
Psychological strain
crisis moments;
life events,
Family demands
PARENTING DEMANDS
ological
upport;
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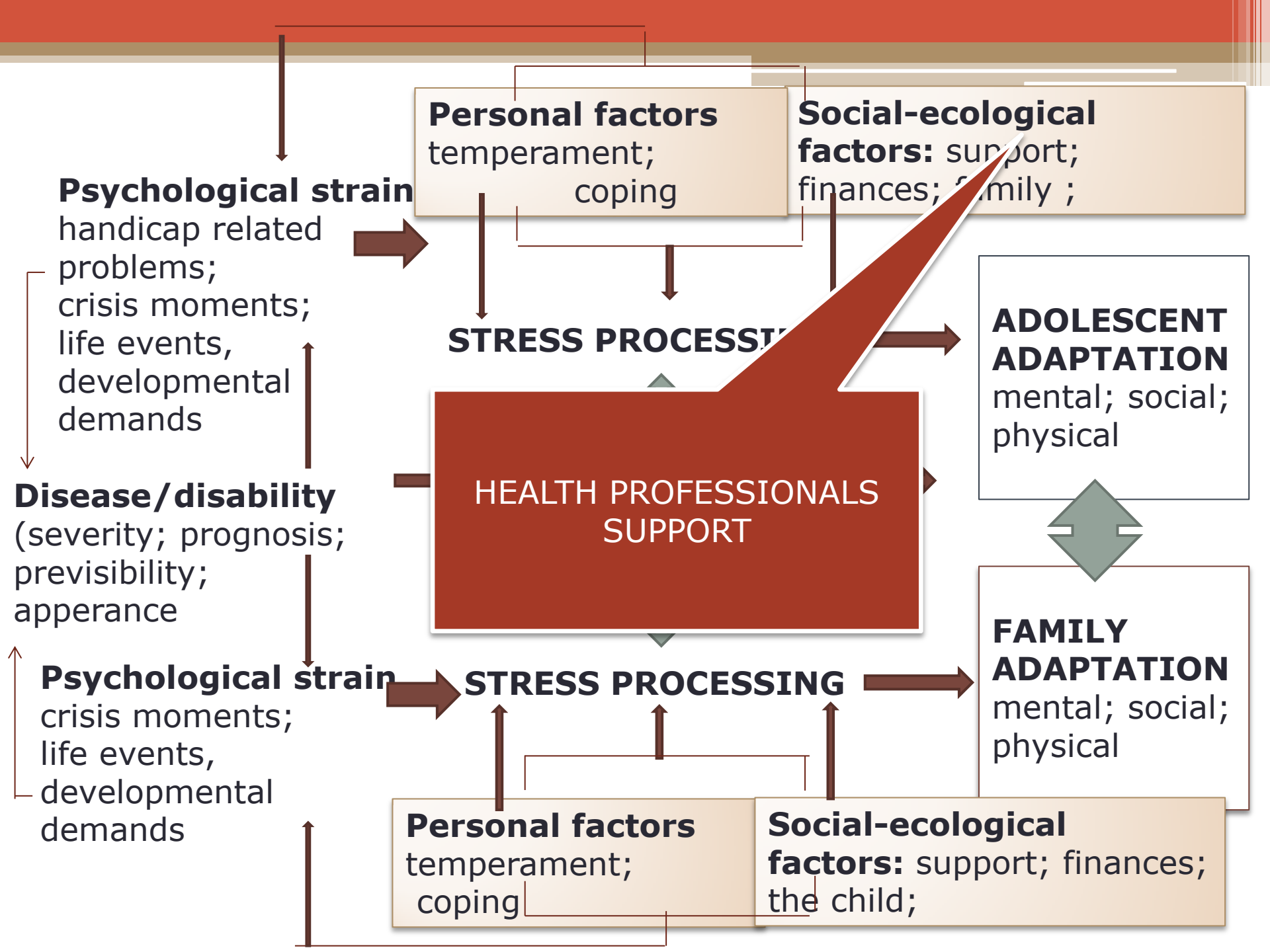
Personal factors
temperament;
coping
Social-ecological factors: support; finances; family ;
Psychological strain
handicap related problems;
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STRESS PROCESSI
ADOLESCENT ADAPTATION
mental; social; physical
HEALTH PROFESSIONALS SUPPORT
Disease/disability
(severity; prognosis; previsibility; apperance
Psychological strain
crisis moments;
life events,
developmental demands
STRESS PROCESSING
FAMILY ADAPTATION
mental; social; physical
Personal factors
temperament;
coping
Social-ecological factors: support; finances;
the child;

IMPLICATIONS

ADOLECENTS DEVELOPMENTAL TASKS/DEMANDS

-

There is no point on going to that party. I am nothing but a good friend. I look like a good friend. A younger good friend!!! I´m am not to be noticed !!

- Girl 15y

(1)

- ❖
- ❖

ristics

uberty

- dis
  dissatisfactio ody;
- peers often rema
  differences in a neg way:
  not being seen as a se
  partner

❖ *Sense of isolation from peers*
❖ *Diminish self concept : self competence*

Depression
Anger

IMPLICATIONS

ADOLECENTS DEVELOPMENTAL TASKS/DEMANDS
- *THE ADOLESCENT AGENDA – " a child never more"*

(2) AUTONOMY; PRIVACY; INDEPENDENCE

Being in control of his life

Emotional and physical privacy

Perspective financial independence

Disease Characteristics
- Time of diagnose
- Crisis (recorrent)
- Treament
- Prognosis

- Recurrent experiencies of dependence and lack of privacy
  every day treatment
  burden
  frequent hospitalization

- ❖ *Lack of self efficacy*
- ❖ *Ambivalance towards the future*
- ❖ *Lack of privacy*

Anxiety
Rebellion
Aggressiveness
Poor adherence

- Finish school / frequent absentism
- Career/ prognosis

IMPLICATIONS

ADOLECENTS DEVELOPMENTAL TASKS/DEMANDS
- *THE ADOLESCENT AGENDA – " a child never more"*

(3) ESTABLISH NEW RELATIONS

Old relations with new rules

New, private, emotional progressive long lasting relations

Disease Characteristics
- Time of diagnose
- Crisis (recurrent)
- Prognosis
- "Visible" characteristics

Dependence from "old" relations
Lack of normative developmental experiences
Lack of emotional privacy
Overprotection

Ansiety
Depression

Revelion and conflits

IMPLICATIONS

PARENTING
- PARENTS (AND OTHER ADULTS) AGENDA

(1) ADJUST AND ACCEPT PHYSIOLOGICAL CHANGES

(2) AUTONOMY; PRIVACY; INDEPENDENCE

(3) ESTABLISH NEW AND ADULT RELATIONS

(1) HEALTH AND RISK TAKING BEHAVIORS

(2) PREPARE FOR INDEPENDENCE: ……. *Let go*

(3) ADAPT TO "NEW" RELATIONS

IMPLICATIONS

PARENTING

(1)HEALTH AND RISK TAKING BEHAVIORS

(2) PREPARE FOR INDEPENDENCE: Let go

(3) ADAPT TO "NEW" RELATIONS

Over vigilance
Over protection

Less tolerance
Dependence reinforcement

- Conflicts
  - with the adolescent
  - between parents
  - among siblings
- Parental emotional disruption
- Barrier to adolescents developmental goals

Vulnerability: physical heal

Parental significations of their *agile"*

DISEASE IMPLICATIONS ⟷ PARENTAL BELIEFS

IMPLICATIONS

PARENTING

(1)HEALTH AND RISK TAKING BEHAVIORS

(2) PREPARE FOR INDEPENDENCE : Let go

(3) ADAPT TO "NEW" RELATIONS

Difficulty in delegating responsibility for treatment

- Conflicts
- Poor adherence
- Increased health risk behaviors
- Dependence
- Parental emotional disruption

Time of diagnose and respon

Parental role as caretaker

DISEASE IMPLICATIONS

PARENTAL BELIEFS

HEALTHCARE PROFESSIONALS - Support and **Management of Cystic Fibrosis in the adolescent**

(1) Prepare family and child before adolescence : "anticipate problems and discuss solutions" (*e.g* show interest and listen to child and family developmental issues)

(2) Respond to emotion – listen carefully and give time to hear their feelings

(3) Be open (and prepare) to discuss adolescent agenda
Don´t judge and don´t paternalize: use " you must" as seldom as you can

(4) Involve the family and be aware of "over(s)": over reaction; over protection

(5) Be trustful (confidentiality; loyalty)

(6) Involve the patient – the more involved the adolescent is in decisions and treatment the more he will be responsible for his health (from the age of 6, children can understand medical topics. Adherence can be enhanced if the adolescent understands, feels competent and accepts treatment

(7) Set limits from the beginning (be consistent in there use). The adolescent must be able to predict your response.

(8) Uncenter families from the disease: reinforce parents; promote life beyond cystic fibrosis

9) A multidisciplinary team is essential – doctors, specialist nurse, psychologist, dietician, physiotherapist, occupational therapist and social workers must respect each others and discuss the patient's care in interdisciplinary meetings

(10) Be present during TRANSITION to adult health services

A CASE……..

John is a 16 year old boy with FC. He was diagnosed when he was 1 year old, after a long history of lung infections (that almost killed him). It was a very traumatic time for his parents! John is clinically stable but all of his 16 years were of struggle. His mother always keeps an eye on him. She stopped working and became his primary care. His father helped but he never recovered from the diagnose and sometimes copes by avoiding. He says that *"it is very difficult for me to know what to tell him. I think my wife does it better. I just what him to be well and happy" .* They decided not to have more children.

John was always a quiet boy. Sometimes he cried during treatment and complained about hospitalization and medical procedures but most of the time he accepted it. He was always very close to his mother and often she told you " *he makes me feel that I am needed. He is my life. I know that I have (we have) defeated dead."*

During the last medical appointment John's mother was very anxious and said "*I don't know what is happening. I know he is an adolescent but he was so well until three months ago! I don't know what to think and I am very frightened. Please talk to him. He never comes home in time. When he is home he doesn't talk to me. He goes to his room and shuts the door. He didn't want to go to physiotherapy last week and was quite aggressive to me about that, saying that from now on he would only go when he needed it, and that it was something for him to decide. He no longer goes out with his long time friends. I think he lost some weight and he looks pale. I am so, so, worried. I don't know what to do. The last 16y of my life where devoted to him and now I am afraid I am loosing him for ever! I know he is going to get sick. You know that he can not adopt an unhealthy life style . That is what I keep saying to him but he shuts the door on me. Help me! My husband is also terrified but keeps saying that I will know what to do. But I really don't!!!*

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