A Portuguese intervention model for parents of children with chronic illness

Luísa Barros
Margarida C.Santos

Universidade de Lisboa
Faculdade de Psicologia
lbarros@fp.ul.pt

Parenting a child with chronic illness is:

Demanding – parents need to respond to all the demands of raising a child + caring for a sick child;

Continued Task – 24hours over 7 days a week, coping both with routine and new situations and sometimes acute or very severe problems;

Multidimensional – cognitive, emotional, behavioral physiologic dimensions are involved;

Unique to each person/family, to each illness, to each developmental stage, and so on, but also *with some Common Dimensions*.

Many families of children with chronic illness are very resilient and adapt quiet well to the multiple tasks and demands,

but others need some form of support and education in different stages of the process of adaptation, so that they can develop alternative ways of coping with the situation.

Foundations of the Intervention

Our studies about parents meanings and experience of raising a child with different illnesses and situations:

- Populations of parents of children: Premature, Asthma, Cardiac Disease, Diabetes, Chistic Fibrosis, Spina Bifida and Down Syndrome;
- Understand the subjective meanings about the illness, about the major issues and problems, about coping and problem-solving strategies and about their preferences regarding communication with health professionals and social support;

Literature on parents adaptation to pediatric chronic illness (*e.g.,*Thompson, 1994; Wallander & Varni, 1992)

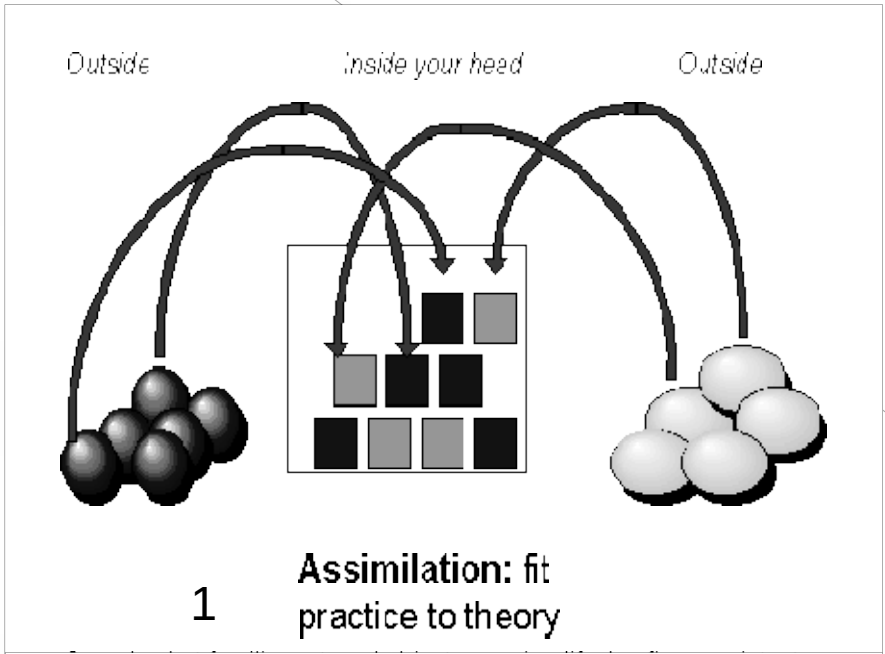
Foundations of the Intervention:

A structured, clinically oriented model

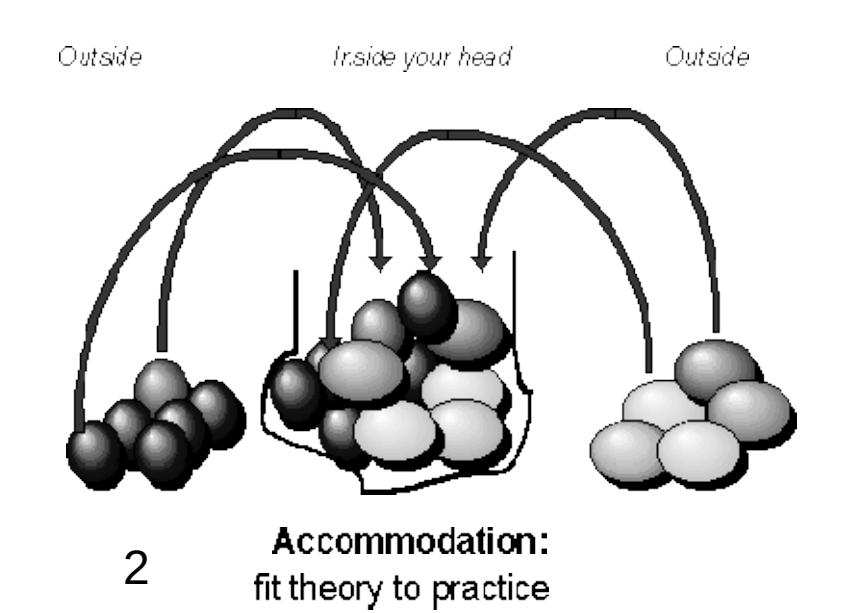
Based on major assumptions:

- **Meanings** about illness and development, and about parents role as educators and caretakers are in the core center of their attitudes and their overall adaptation;
- Most of the times parents are already doing many things well and effectively **and can learn to do better.**

Changing beliefs is a complex process that implies assimilation and accommodation



Complex ideas are simplified to fit in the existing categories



You have to change the categories to fit the new ideas

1. In **Assimilation**, new information, new perspectives, are incorporated into the internal world without changing the structure of that internal world.

2. In **Accommodation,** the internal world has to **accommodate** itself to the evidence with which it is confronted and thus adapt to it, which can be a more difficult and painful process, but leads to a more stable change.

Methodologies:

The most effectives methodologies to help parents change are:

- Helping parents recognize their perspectives and their most usual attitudes and behaviors –
  - Self-monitoring
  - Discussing and reflecting about one's perspectives and attitudes

Modeling and discussing different perspectives (meanings) and strategies:

- *Cognitive Decentration* by viewing "alternative models"
- Rehearsing new attitudes and behaviors

Systematizing strategies to use in the future

Objectives:

- Preventive
- Health Crisis
- Reference by other health professionals: emotional disturbance /Non-adherence

Subjects

- Parents/Family of children with a chronic situation
- Individual or in Groups

Format:

- Programs directed to the phase and objectives identified to each individual/group situation
- Consulting interventions with main health caretakers: physicians, nurses, physical therapists, teachers…

1 - Knowledge and Meanings about the illness

“It is not the symptoms themselves that are significant in comprehending illness behaviour, but the way in which they are defined.”

Knowledge and Meanings about the illness: symptoms, evolution and treatment

Help parents develop an accurate, integrated and positive perspective about the illness;

Help parents deal with causes when this is still an important issue:

- Understanding of causes may influence adaptation and behaviour

Help parents indentify the major consequences of the illness:

- Importance of differentiating consequences of the illness and consequences of educational attitudes;
- Understanding multiple causes and consequences and the role of parental behaviour and educational context in mediating between illness and child output;

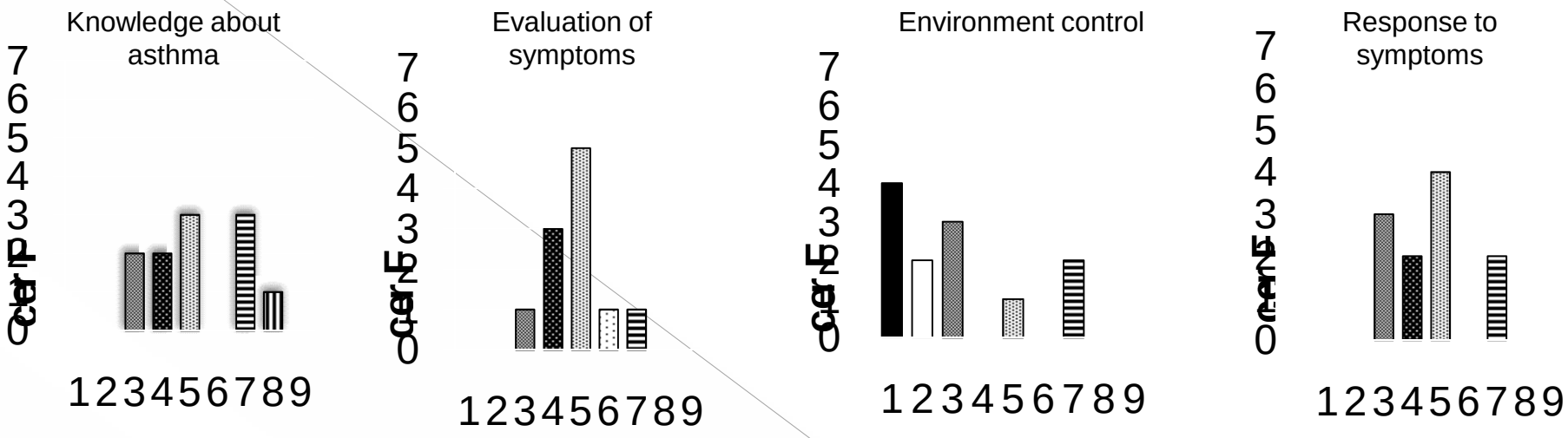
Help parents anticipate future issues and problems, when appropriate.

Knowledge and Meanings about the illness

Methodologies:

- Presenting new information: *What do I want/need to learn?*
- Promoting information-seeking attitudes: *How can I find relevant information?*
- Acknowledging existing beliefs: *What do I believe about this illness? Or about treatment? Prevention?*
- Applying information: *What does this means to my child? To me? To my family*
- Cognitive restructuring: *What is the best way to think about this? What should I pay attention and focus know? How can I change the way I think about the illness or the treatment?*
- Analyzing and discussing different meanings: *What is the best way to think about this issue? To help me be in control? To help my child develop? To help my child feel secure and happy?*

EXAMPLE: Knowledge and understanding of the illness (Silva & Barros,2010) *Family Asthma Management System Scale* (Klinnert e McQuaid, 1997)



Good knowledge:

Basic knowledge of asthma as a disease that affects lungs and breathing
Knowledge of main symptoms
Knowledge of medicines (name, dose, time of administration)
Some knowledge about environment control

Major difficulties:

Understanding asthma as a chronic inflammation
Understanding medicines action.
Understanding the role of triggering factors
Understanding the need for medication when child is well
Valuing of some environmental factors (e.g., fathers smoking)
Recognizing the early signs of an episode

Example:

- **Bronchodilators**

  Action: dilating the bronchial muscle

- **Anti-inflammatories**

  Action: controlling and reversing the bronchial inflammation

Imagem retirada de: www.pueri.com.br/asma.gif

How do I think about Asthma?

› How do I want to think about asthma?

1. 

Asthma is a serious disease that will be present in our lives forever. My child will suffer all his life with this horrible crisis!

2. 

Asthma is a serious disease that will be present in our lives forever, but we can control symptoms so that he doesn't suffer that much!

3. 

Asthma is a serious disease that he will have to life with always, but we can learn to cope, so that he may have a good quality of life!

4. 

_____
_____
_____
_____
_____

2 – Coping strategies
3 - Problem-solving strategies

Changing coping and problem-solving strategies is a complex process that implies:

Motivation:

- Recognize some degree of dissatisfaction with the present situation and desire to change

Learning:

- By observing models, by suggestion, by reflection

Practice:

- Planning rehearsal situations and reflecting about experience

Coping Strategies

Different strategies are useful for different situations

Some strategies are positive at short term, but may be negative at long-term, or if repeatedly used

The most effective coping involves some change in the meaning of the situation and the use of different, multiple strategies

Most parents are able to identify and use positive strategies; but they can learn to improve their use of useful strategies.

Coping strategies most identified by parents (Santos,2005; Santos e Barros, 2006; Barros & Santos,2009)

Normalization/ Restructuring of daily family and child life

Positive Reassessment*

Attention centred on everyday tasks*

Valuing the positive and normal aspects of the child's life*

Planning *

.../...

*Considered more effective by parents.

Attention centred on learning treatment competence

Attention centred on the improvement of the child clinical condition

Repetition of optimistic/positive verbalizations

Information search/Trying to know more about the disease

Avoidance of difficult themes or issues

Religion/Spirituality

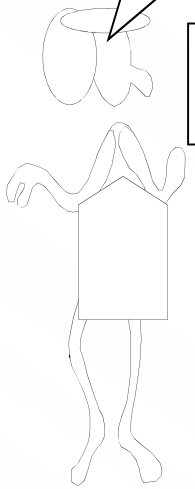
Comparing with other's similar or worse situations (the least worse)

Problem postponement

Seeking Emotional Support

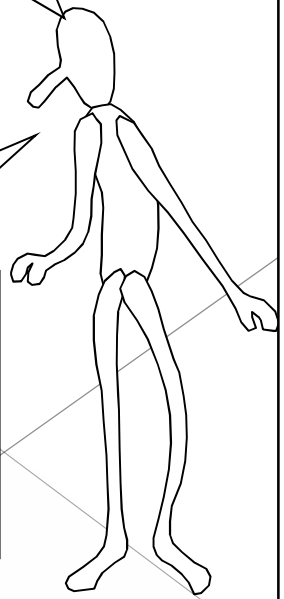
Presenting different, alternative models:

Usually I try to think only what is my next task: today we will be able to …..



When is this thought useful and positive?

I try to think: she is a happy child, she enjoys playing and going to school…



Sometimes, this is not very useful, mainly when she is sad, tired….I need another strategy for these situations!

Problem-solving strategies

In different stages of the illness/of adaptation, different problems acquire importance,

Parents tend to use both useful and ineffective strategies,

Parents feel compelled to solve some problems , mainly related to treatment or symptoms control *“no matter what”; “I will do anything to make her eat” “I try everything possible*”,

We observed very little reflection about these educational strategies- acknowledging ineffectiveness promotes change

We observed *persistence in ineffective strategies* and consequent anxiety and frustration, or minimization of educational, long term issues and problems “*As long as I am able to have her eating and growing ... I don’t have the energy to think about other issues!”*

Problem-solving strategies
How mothers think about the problem (To themselves):

Attribution of causes/justification to the problem *“I think this is due to too much pampering”…this is normal in a child her age…they are all the same”*

Classifying the problems/defining different levels of importance/severity *“ I try to understand why this is happening…if she wants something reasonable, or if she is too tired, I may accept; if it is only a tantrum with no reason, she has to comply!”*

Understanding/empathy with child's experience *“ I pity her for not being allowed to eat what others eat… I would feel angry too!”*

…/…

Problem-solving strategies (Marques,2010; Santos, Barros & Marques, 2010)

How mothers think about the problem (To themselves)

Imperative need to solve the problem by centering on the negative consequences:
"What I think is that this is very important, and that if he does not eat, the consequences can be dramatic!

…/on positive consequences: *"I think that this is the better for her, and so the sooner the better!"*

Rationalizing *" I understand she doesn't like to take the pills, but I know it is for her own good, she needs this to go on!"*

Trying to control emotions before acting

" I try to keep calm and wait to see what happens next";

"I calm myself before talking to him"

Problem-solving strategies
what mothers do about the situation (with the child)

Changing the concrete situation to minimize costs/ difficulties to the child *"I mix the food with some sauce, or prepare the food that she likes"*

Distraction *" I tell him a story or try to distract him for a while"*

Facilitating child's emotional expression *" I ask her what she is feeling, what she wants"*

Attention withdrawal/extinction *" I pretend I don't see or hear; I let him cry for a while"*

Modeling " *I show her what to do, that she can try to think about good, beautiful things* "

.../...

Problem-solving strategies what mothers do about the situation (with the child)

Presenting rational arguments to the child *" I explain to her that she is thinner than others, so she need to eat more"*

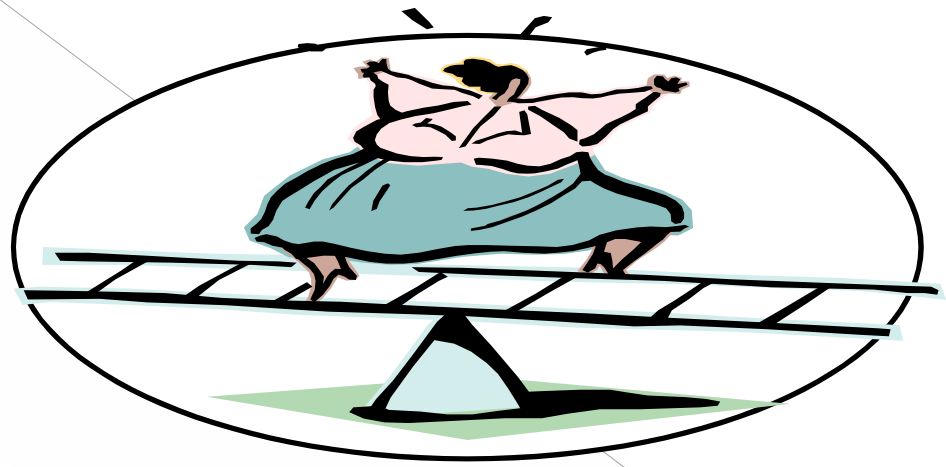
Verbal punishment **"** *I get very angry and tell her I am mad about it"*

Threatening to punish *" I tell her that if she does not eat, she will be much worse and will need to go to the hospital!"*

Giving up/(letting the child "win") *" Often I give up and don't give her the supplements that she hates…we get so tired…!"*

4 – Control Attribution

Gaining more control over the situation - increasing self-efficacy



Realistic demands
High control
High self-Efficacy
Positive expectations
Positive affect

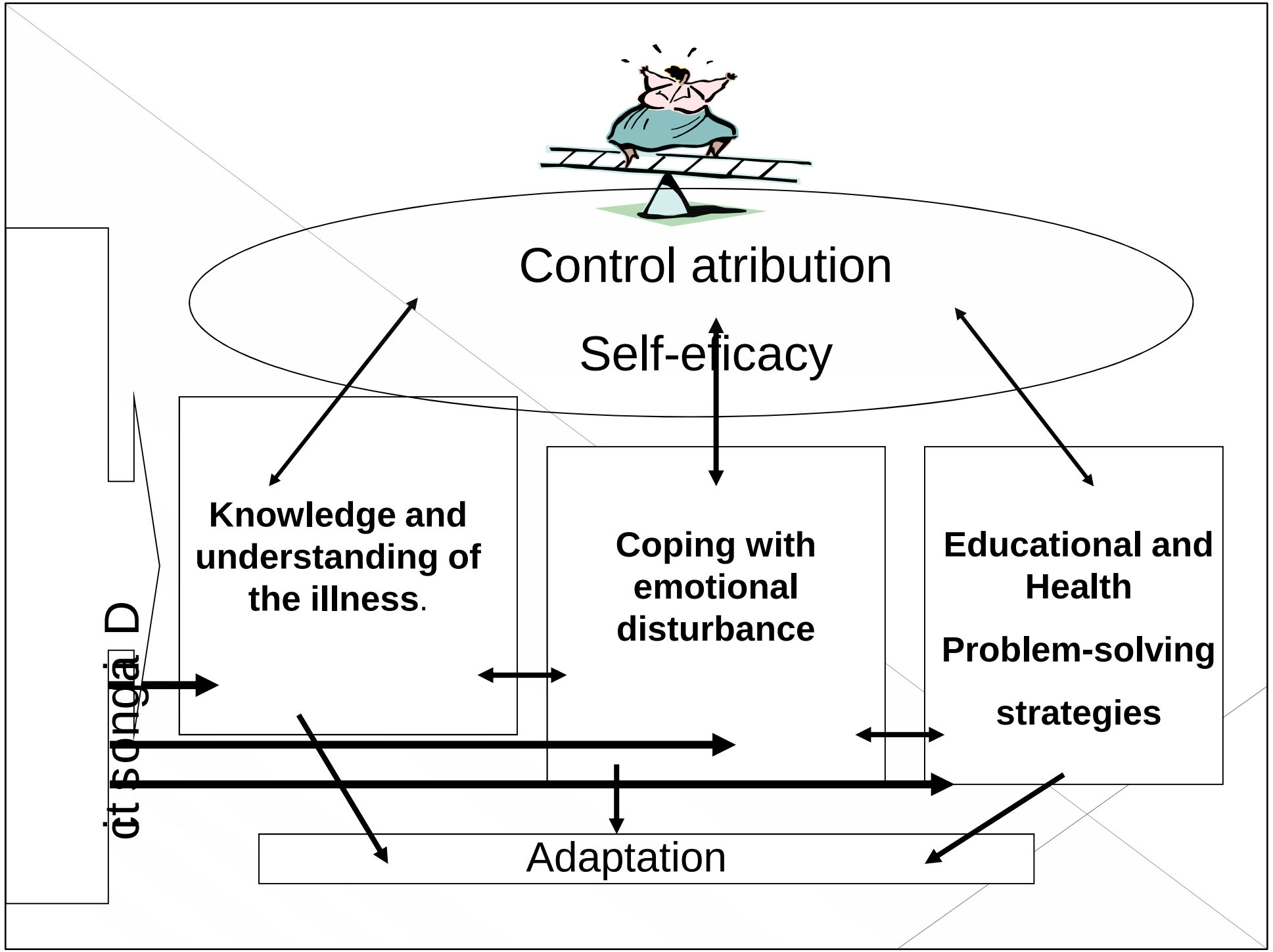
Unrealistic demands
Lack of control
Low self-efficacy
Negative expectations
Negative affect

Gaining more control over the situation- increasing self-efficacy

The opportunities to :

- Gain a more positive and realistic perspective about the situation of educating a chronically ill child;
- Select more concrete objectives, defined by small , progressive changes that can be observed and monitored
- Use more effective coping strategies to feel more calm and in control of the situation
- Use more effective strategies to solve educational and health problems and so receive more positive feedback

All contribute to change the evaluation of control and self-efficacy


Control atribution
Self-eficacy
Knowledge and understanding of the illness.
Coping with emotional disturbance
Educational and Health
Problem-solving
strategies
Adaptation