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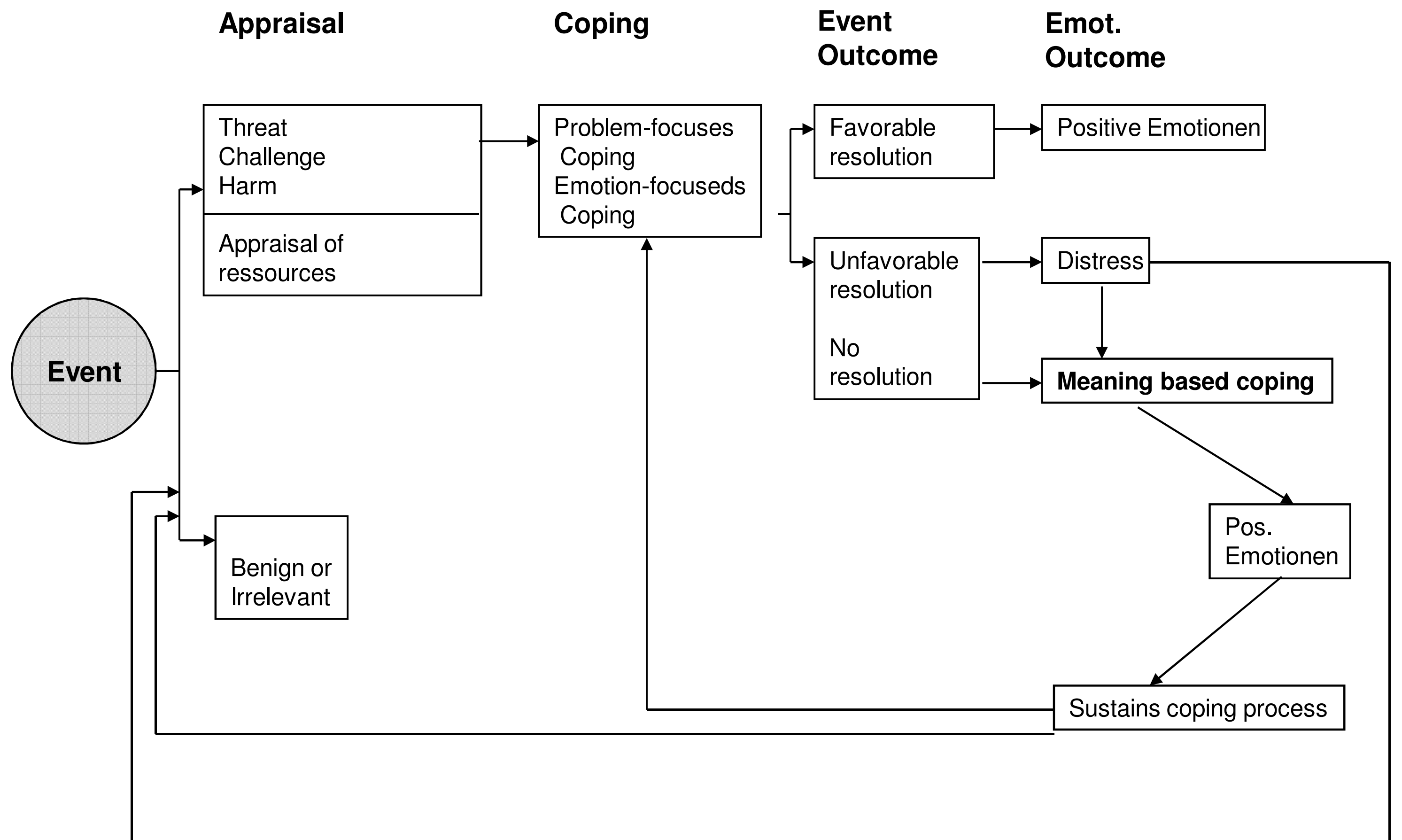
Problems and establishing a relationship with problems

Stress model of Lazarus and Folkman



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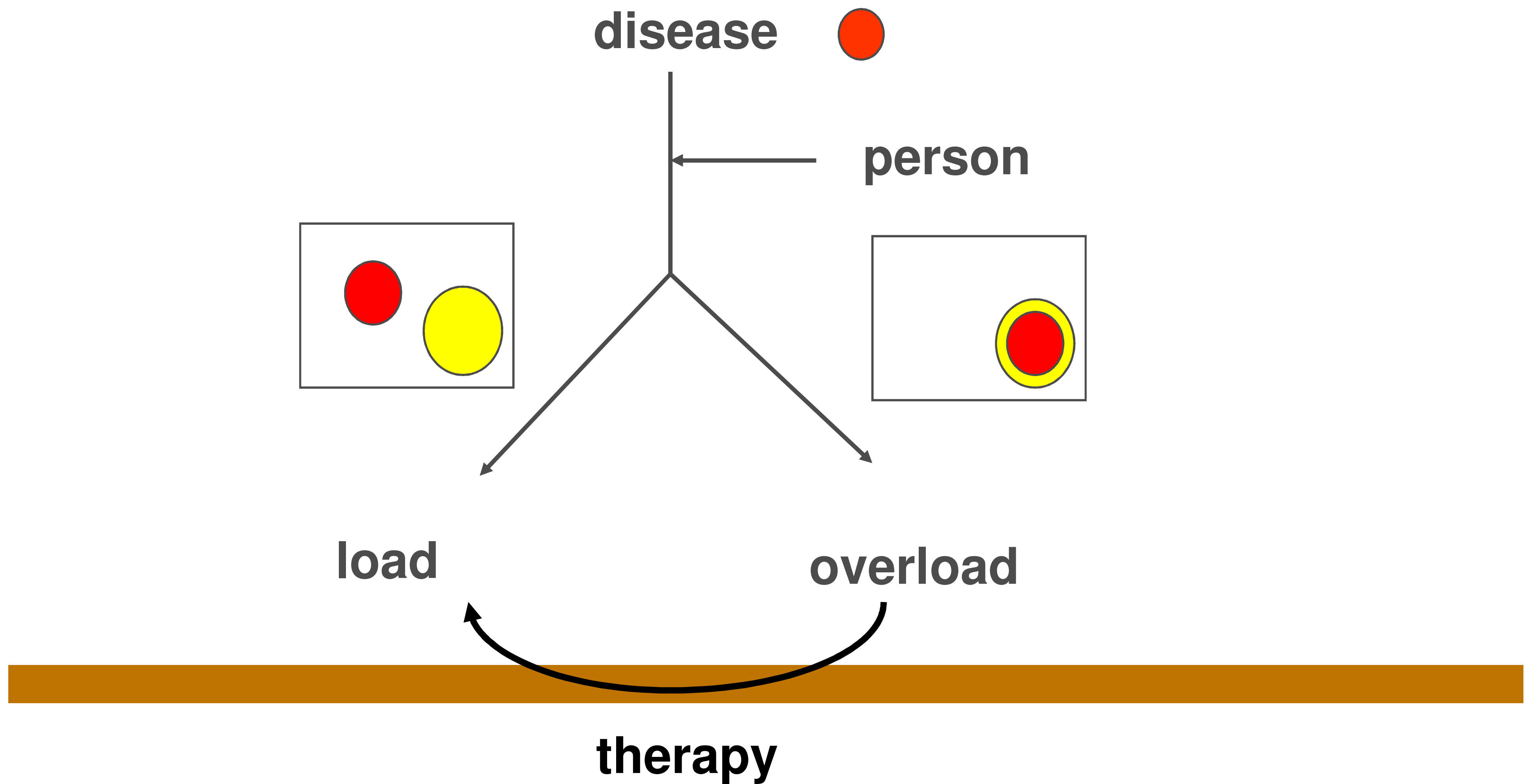
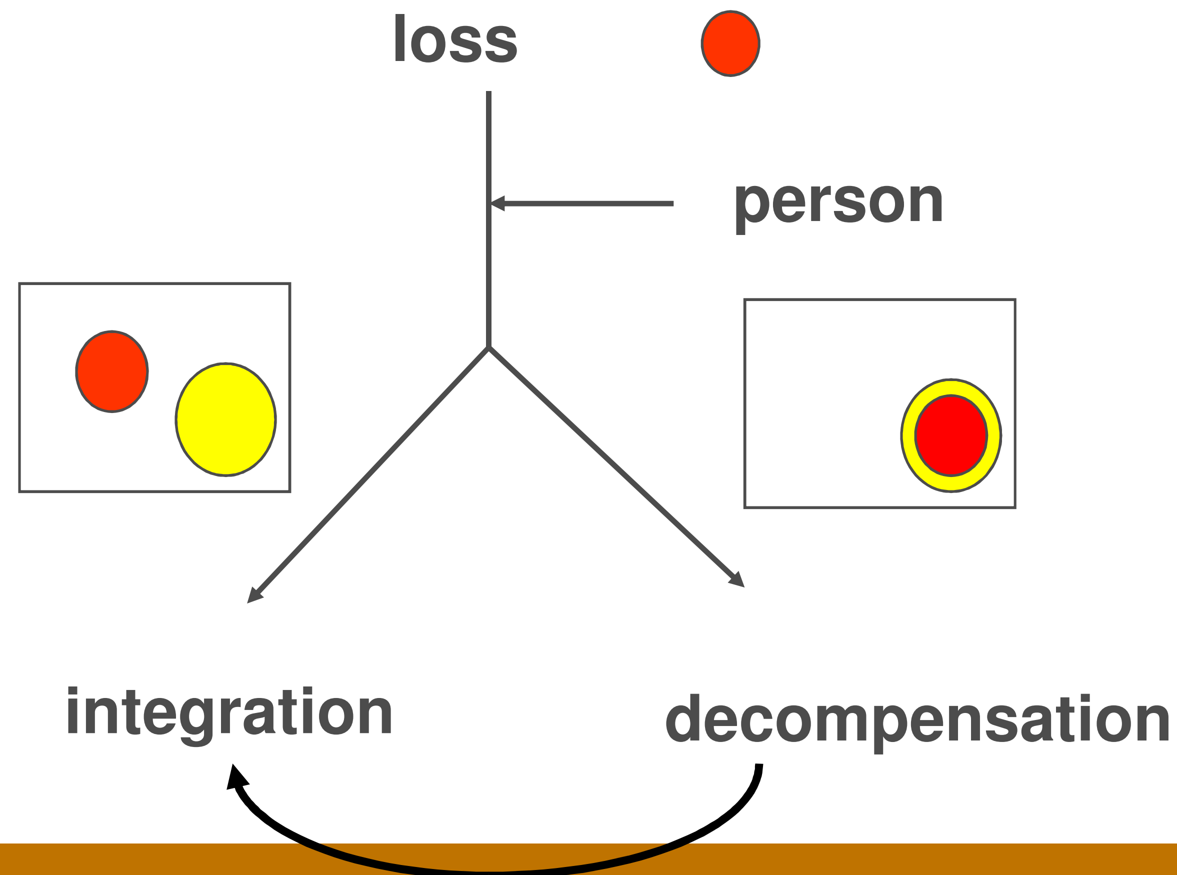
THERAPY IN PATIENTS WITH CHRONIC DISEASE



HEALING PROCESS AFTER LOSS



PRISM- development, validation process, clinical use, scientific data

PICTORIAL REPRESENTATION OF ILLNESS AND SELF MEASURE (PRISM)

- Initially aimed to develop a simple visual method of assessing coping
- Pilot work demonstrated that the PRISM instrument was not measuring coping
- Evidence from patients with physical or mental disorders indicates that PRISM measures the burden of suffering due to illness - *Leidensdruck* in German
- From the existing literature, it appears that PRISM is a generic measure of suffering
- Important aspects (related) appear to be *illness intrusiveness* and *controllability*

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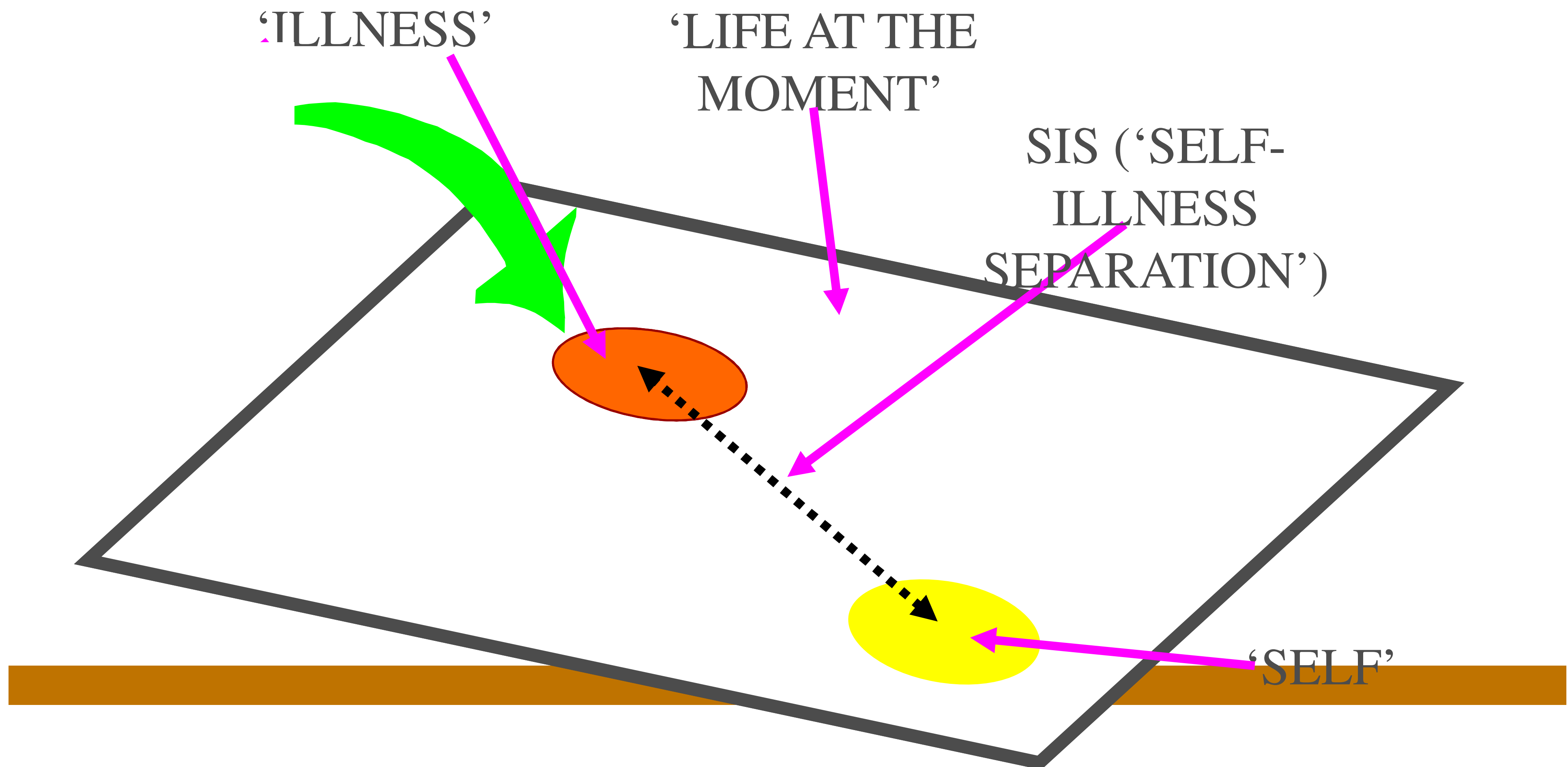
PRISM (PICTORIAL REPRESENTATION OF ILLNESS AND SELF MEASURE)



PRISM IN RHEUMATOID ARTHRITIS
Comments about Illness (low SIS)

- It's really part of my life .. It's also part of who I am (SIS=1cm)
- It's always there - it'll never be away (2cm)
- It dominates my life. When I was younger, I could cope better .. So I would probably have put the illness a bit further away (3cm)
- My illness is part of myself .. It has to be central (3cm)

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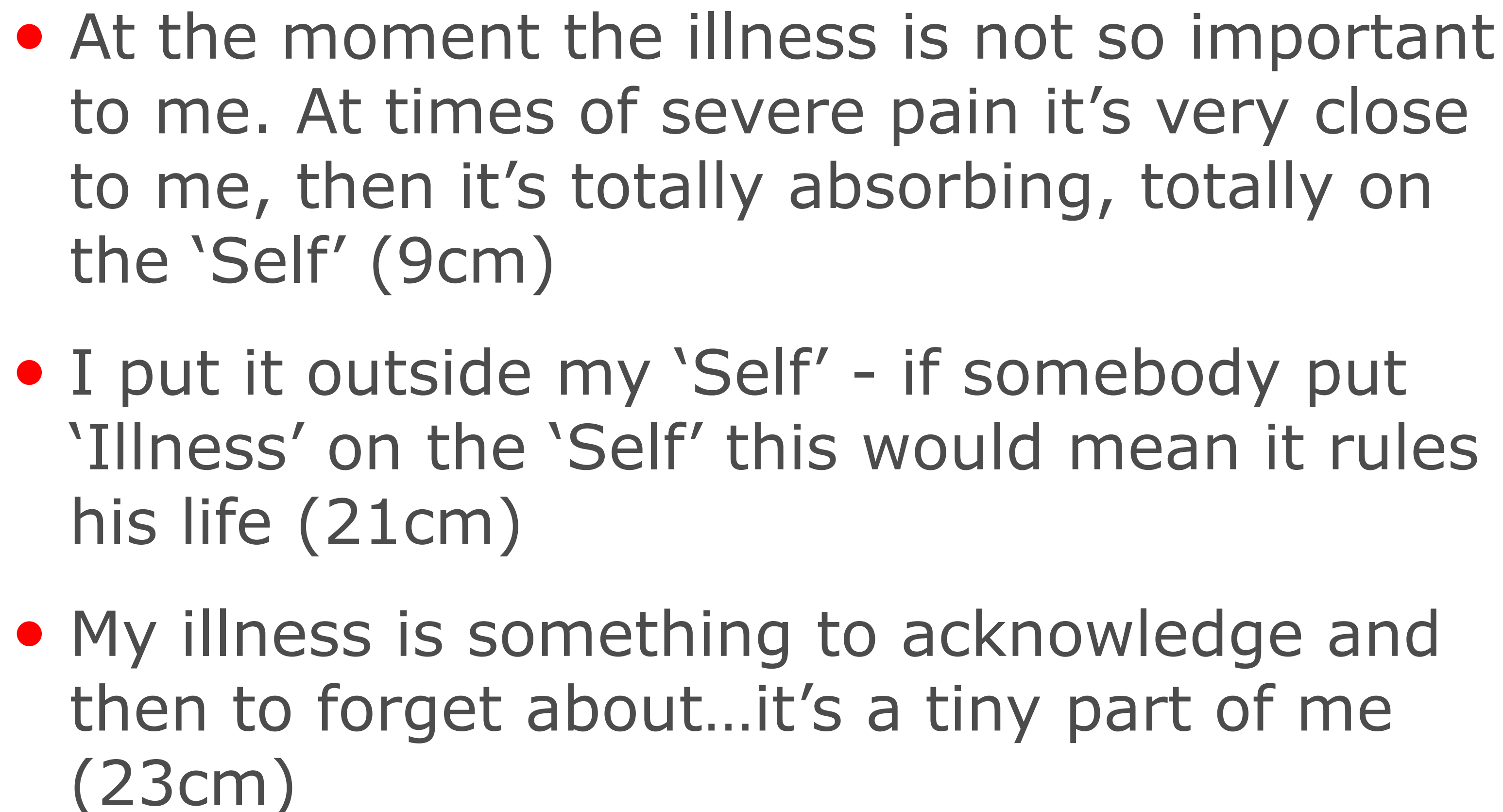
PRISM IN RHEUMATOID ARTHRITIS
Comments about Illness (higher SIS)



PRISM - VALIDATION

FACE VALIDITY	✓
CRITERION VALIDITY (comparison with 'gold standard')	✗
CONVERGENT VALIDITY (correlates with depression (-) and Sense of Coherence (+)	✓
DIVERGENT VALIDITY (different correlations with SF-36 subscales in different chronic illnesses)	✓
SENSITIVITY TO CHANGE	✓

Büchi S *et al*: *Psychother Psychosom* 2002; 71: 333-341

PRISM – FURTHER DEVELOPMENTS

Extension to include factors other than illness (PRISM+)	**Büchi & Sensky (1999)**
Allowing informants to choose between differing sizes of illness disk	**Vingerhoets et al (unpublished)**
Using PRISM as a self-completed measure, mailed to informants	**Rumpf *et al* (2004)**
Computerised PRISM measure	**Vingerhoets *et al* and Büchi *et al* (unpublished)**

Suffering, meaning, growth and narrative based medicine

WHY IS SUFFERING IMPORTANT?

Clinicians commonly see one of their principal aims as alleviating their patients' suffering

Public health specialists have a similar view (WHO website has nearly 1200 references to suffering)

Clinical interventions (even those which relieve particular symptoms of illness) may in some instances make suffering worse

SUFFERING

- Is not an keyword in Medline
- Is absent from the indices of major books on health psychology and psychological assessment
- Is a term very commonly used (85’000’000 hits on the internet!)
- Despite its common use, is seldom defined explicitly
- Is commonly (but wrongly) equated with pain or illness

SUFFERING

A state of severe distress associated with events that threaten the intactness of the person

Occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner

Cassell EJ (1982) NEJM 306:639-645

THE PERSON (‘PERSONHOOD’)

Has personality and character
Has a past (accomplishments, failures, etc)
Has life experiences (which influence the meaning of illness)
Has a family and friends
Has a cultural background
Has roles
Has a relationship with herself (eg self-esteem)
Does things
Has regular behaviours
Has a ‘secret life’
Has a perceived future
Has a transcendent dimension (spirituality etc)

Cassell EJ (1991) *The Nature of Suffering and the Goals of Medicine*

SUFFERING vs PAIN

Often (wrongly) equated with suffering
Pain and suffering do not always go together
Pain is more likely to cause suffering when:

- It is out of control
- Its intensity is overwhelming
- Its source is unknown
- Its meaning is very serious
- It shows no sign of ending

Cassell EJ (1962) NEJM 306:639-645

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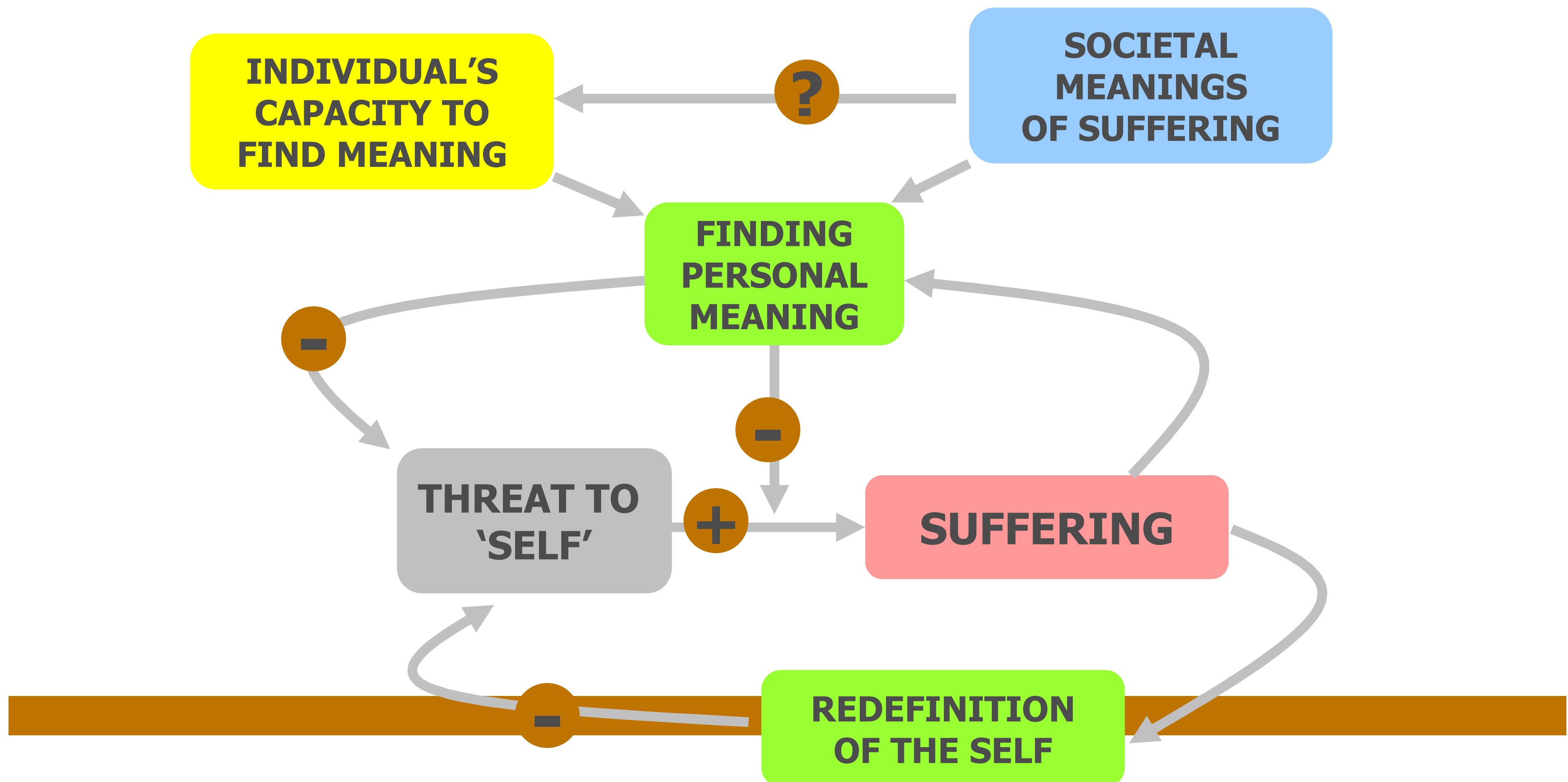
SUFFERING: A BASIC MODEL



SUFFERING AND MEANING

- Discomfort and deprivation are not sufficient to cause suffering; the experience of suffering depends on an experienced loss of meaning and purpose
- Suffering ceases to be suffering when it takes on meaning
- The individual's attitude to his/her suffering is paramount

Frankl VE (1967-84) *Man's Search for Meaning*

ASPECTS OF FINDING MEANING (Davies et al. 1998)

A. Making sense (why me?)
- first reaction after loss
- Quality: rumination
- correlates with symptoms of anxiety and depression

B. Finding benefit (what might be the sense of ?)
- starts at 3-9 months after trauma
- novel construction of construction of self and the world
  Posttraumatic growth

POSTTRAUMATIC GROWTH

„posttraumatic growth is the subjective experience of positive perceived changes after trauma and loss….“

A. Maercker, 1991

DIMENSIONS OF POSTTRAUMATIC GROWTH

- Intimate relationships
- Appreciation of life
- Personal strength
- Spiritual/religious beliefs
- General perspective on life

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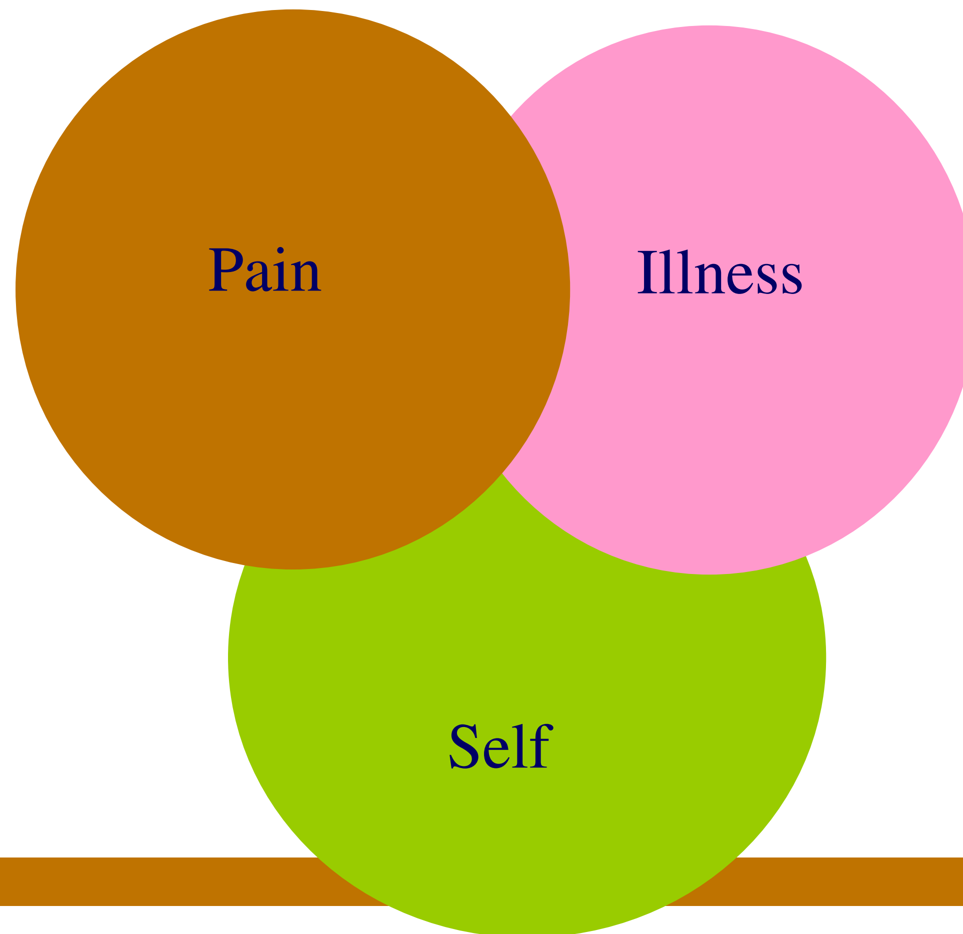
SELF-SCHEMA AMONG PEOPLE WITH CHRONIC PAIN



Individuals have cognitive representations (schemata) of their Self, their illness and their pain

'Healthy' adjustment or adaptation involves separation of the schema for Self, Illness and Pain

T Pincus & S. Morley: *Psychol. Bull.* 127 (5):599-617, 2001

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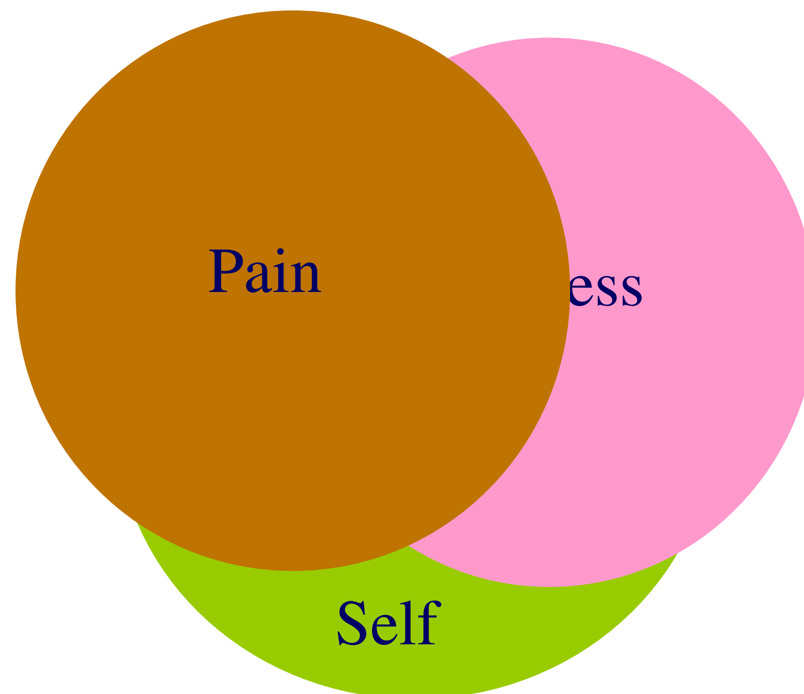
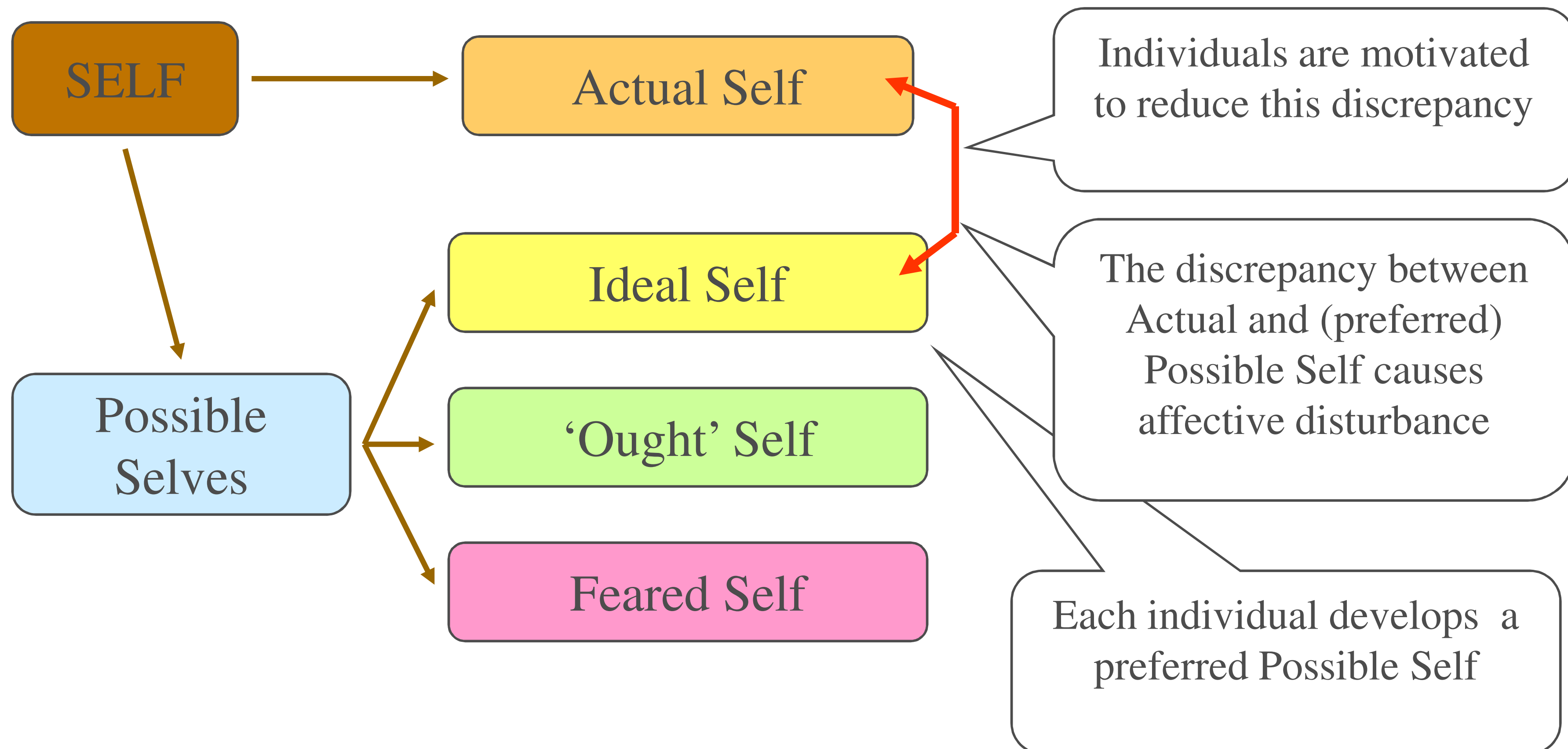
SELF-SCHEMA AMONG PEOPLE WITH CHRONIC PAIN: ENMESHMENT



Distress (??suffering) arises when the schemata for Pain and Illness become enmeshed with the Self-Schema

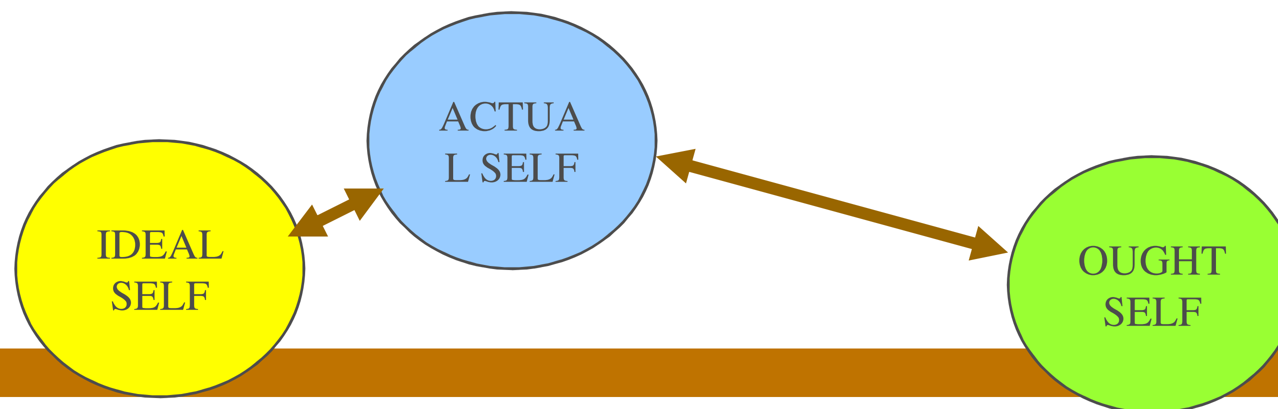
T Pincus & S. Morley: *Psychol. Bull.* 127 (5):599-617, 2001

SELF-REGULATION THEORY OF BEHAVIOUR



After E.T. Higgins, C.S. Carver and M.F. Scheier and others

SELF-REGULATION BEFORE ILLNESS



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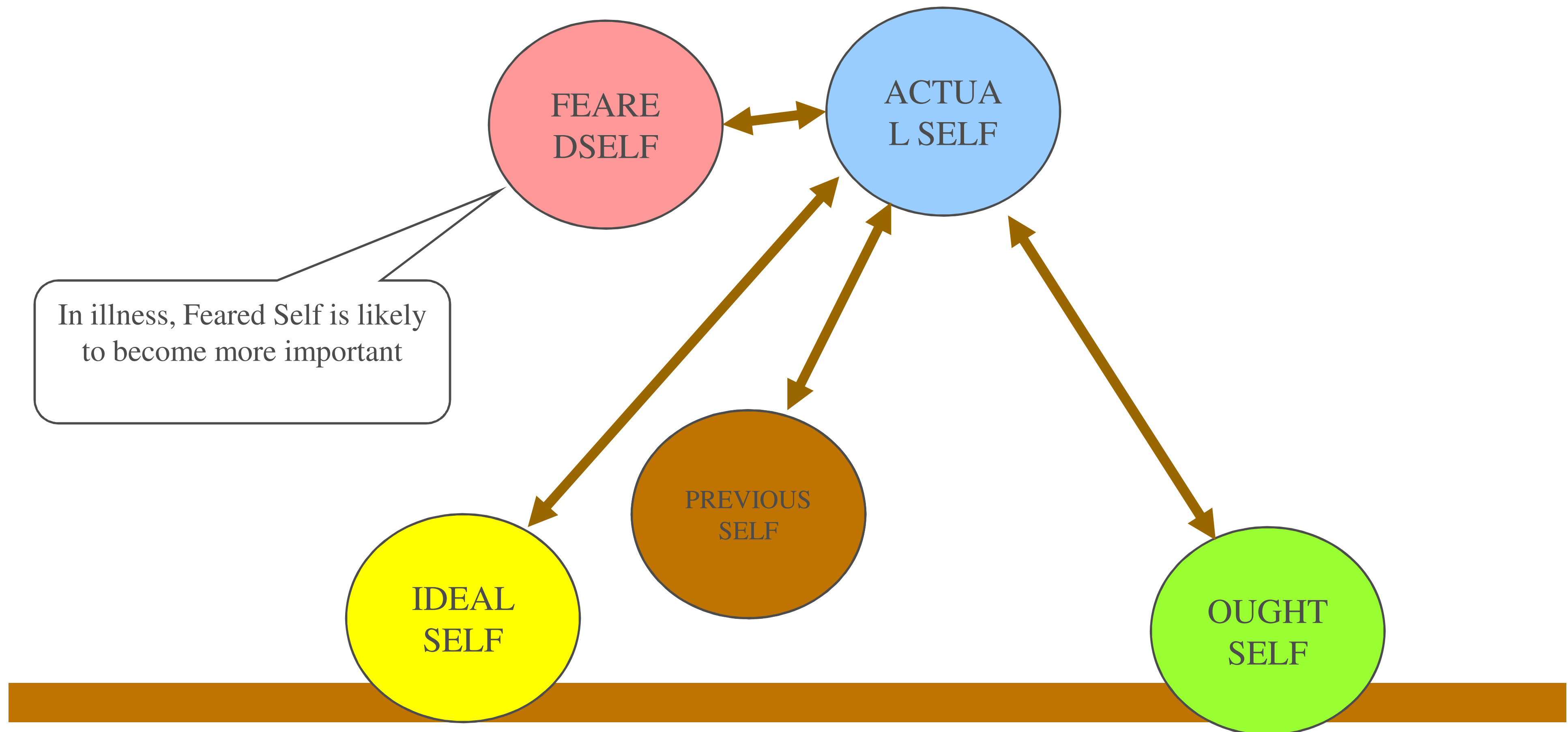
SELF-REGULATION IN ILLNESS



ILLNESS AND NARRATIVES

Narratives normally drive towards ends, preferably tidy ones

The stories that people have in place seldom fit the experience of illness (turning the ill person into a ‘narrative wreck’)

The way out of the narrative wreckage is to continue telling stories – in effect, redefining the Person

Arthur Frank: *The Wounded Storyteller*. University of Chicago Press, 1995

NARRATIVE AS AN ACTIVE AND REFLECTIVE PROCESS

People with chronic illness make sense of their lives through stories

Stories take on different forms and serve varied purposes

Stories of the same event may differ depending upon when and to whom they are told

Stories do not accurately reflect reality – they are *renderings* of reality

THE CONTEXT OF ILLNESS NARRATIVES

Stories are embedded in contexts – not only do they arise in certain situations, but also they often occur within relationships and the course of an illness

What kind of story can be constructed and which story can be told arise within these contexts

Charmaz K (2002)

TYPES OF ILLNESS NARRATIVE AND PERSONHOOD

RESTITUTION	• ***'I was well, now I'm ill, in the future I'll be well again'*** • **?Often Favoured by clinicians**	• **Excludes the need to change the Person**
CHAOS	• **Not really a narrative at all – patient's experience impossible to form into a coherent story** • **The 'narrative wreck'**	• **The Person is fragmented and impossible to define**
QUEST	• **Involves growth or transformation through the experience of illness**	• **Acknowledges the need to change the Person**

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HOW DOES PRISM WORK?

If suffering is an intensely personal experience, subject to individual and societal influences, it would normally be very difficult to discuss suffering without listening to the patient’s narrative to put suffering into a personal context

PRISM appears to circumvent the need for the (contextual) narrative

Might be particularly helpful when the Person constitutes a narrative wreck, (apparently) impossible to put into words

Patient’s response also arguably less influenced by clinician’s/researcher’s attitude than during a narrative

Like ‘starting the patient’s narrative at Chapter 10’

PRISM IS NOT A VISUAL ANALOGUE SCALE

Would be impossible to reframe the current instructions for PRISM to fit a visual analogue scale

Crucial that in the instructions for the PRISM task, there is no explicit mention of the dependent variable (suffering)

PRISM produces a (graphical) summary of the the relationships between illness, Personhood, and ‘life at the moment’ – cannot reduce this to a single dimension

PRISM+: Mrs M

At presentation in the clinic :

- Depressed
  - Sleep and appetite disturbance
  - Poor concentration (attributed to headaches)
  - Constantly ruminating about her illness
- Previously ambitious and very successful in her work, but acknowledged that she had neglected somewhat her husband, family and friends

PRISM+ shortly after diagnosis of MS

PRISM+ before diagnosis of Multiple Sclerosis

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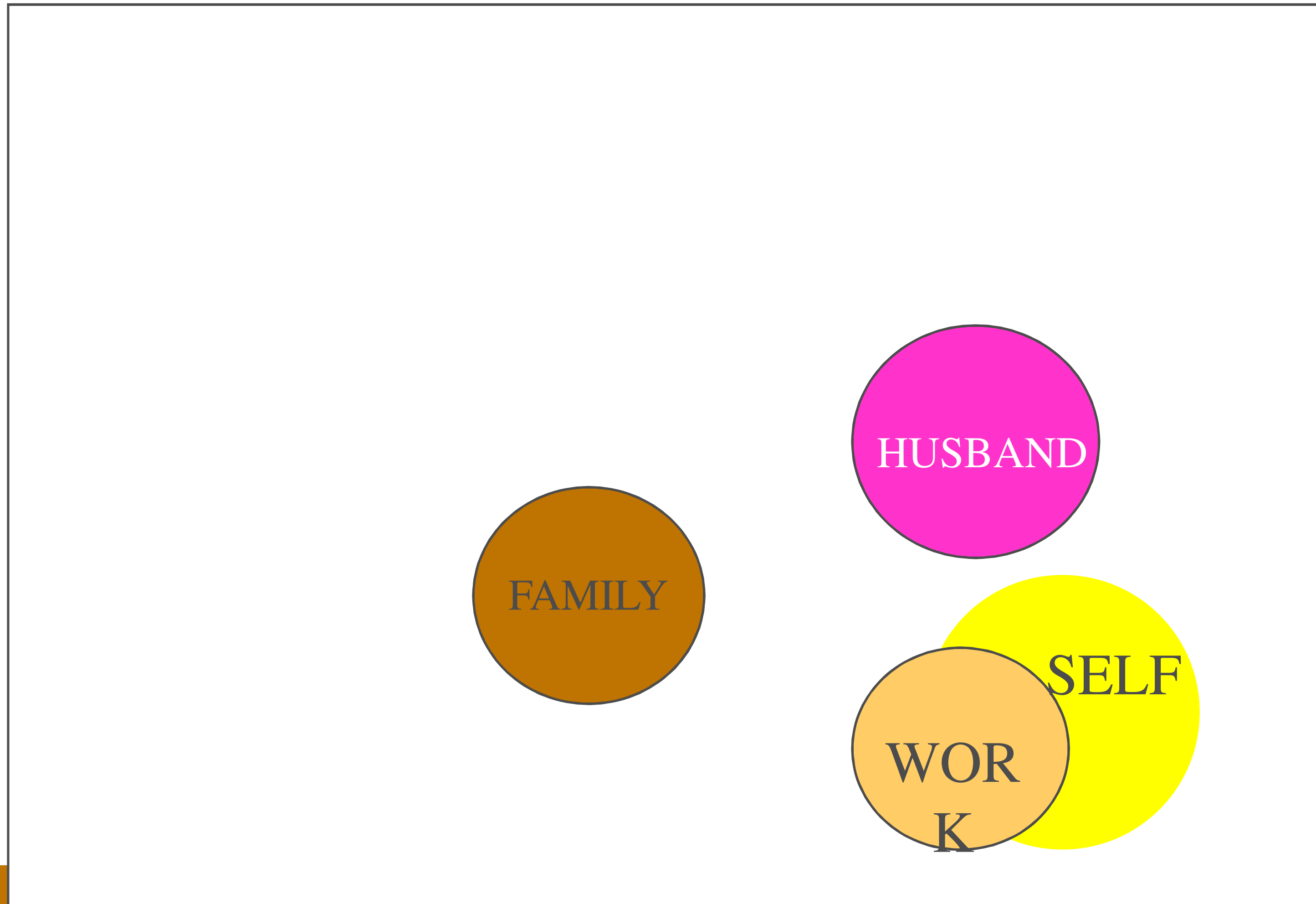
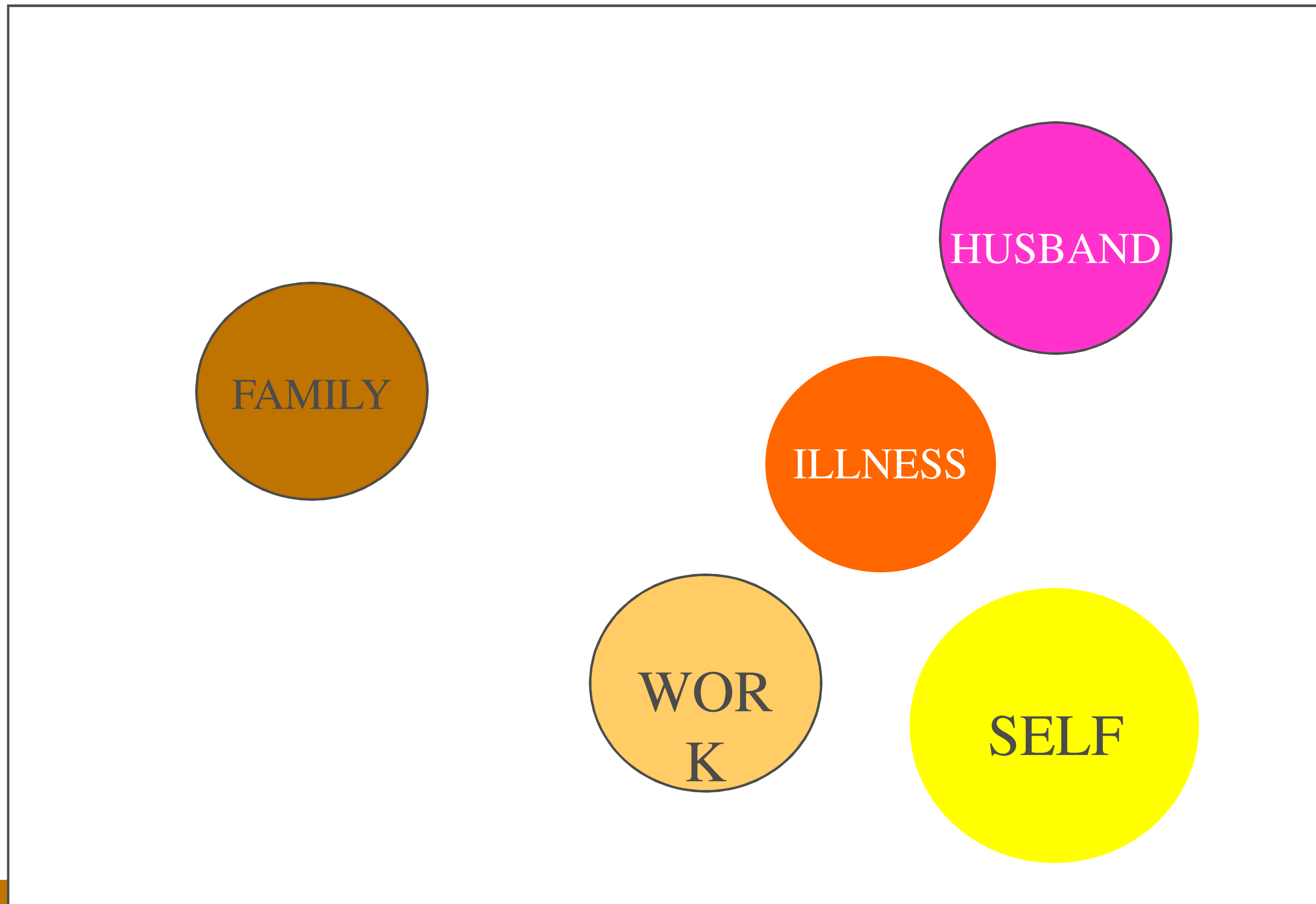
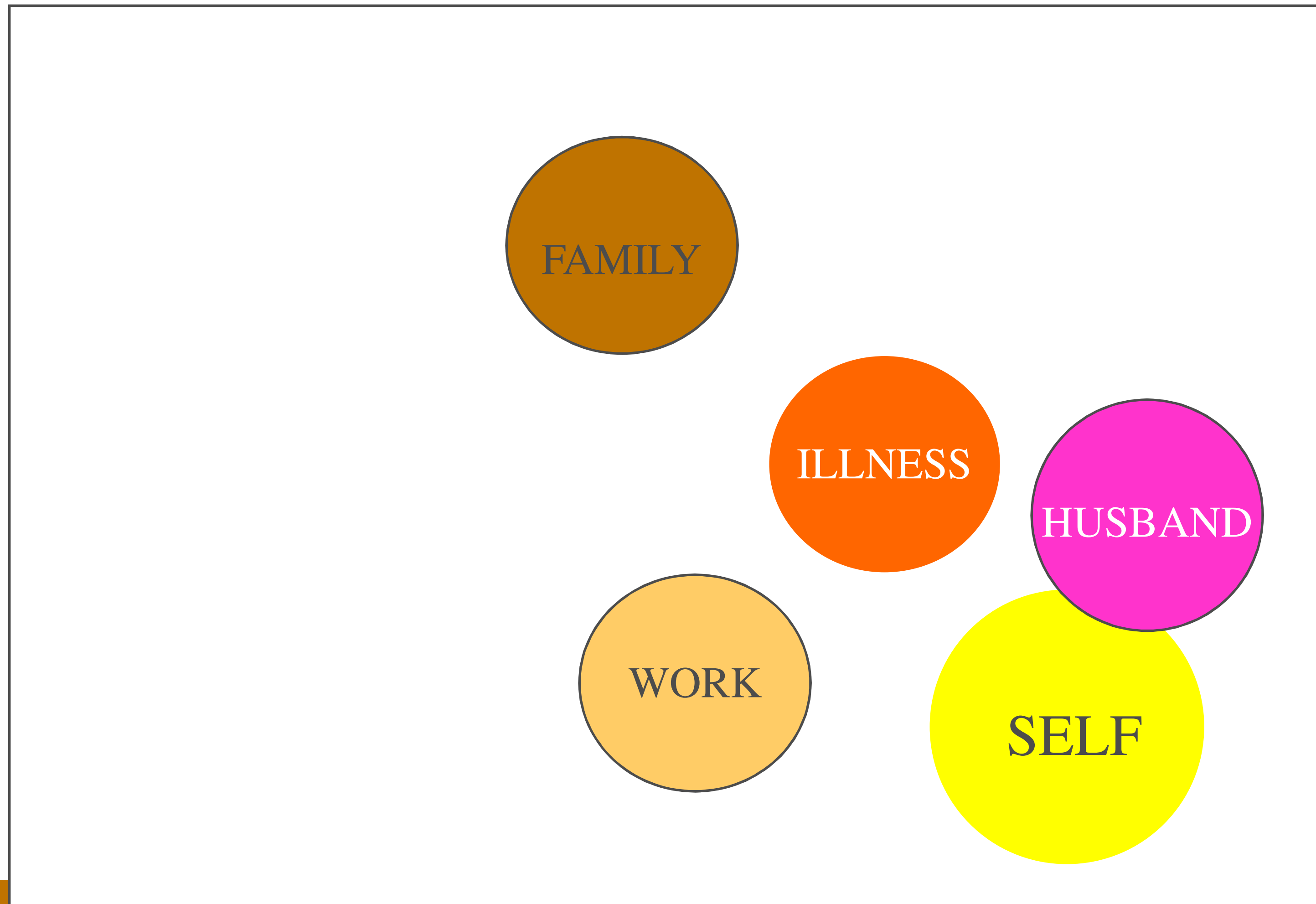


PRISM+ at the end of therapy



PRISM+ at 6-month follow-up



Resources, motivation and therapeutic goals

Patient–Therapist–Interaction: constructive

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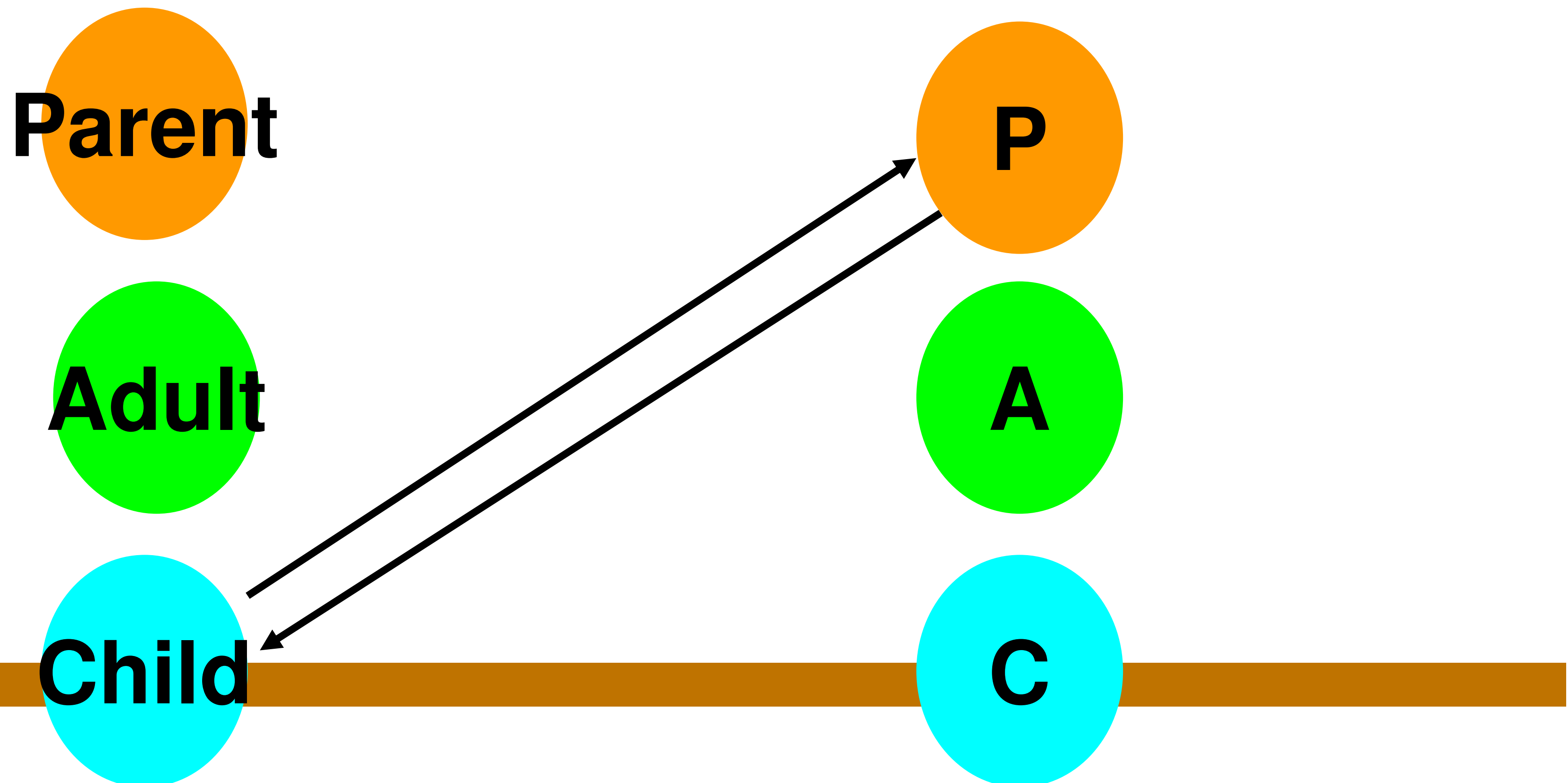
Patient – Therapist Interaction in chronic disease - disturbance



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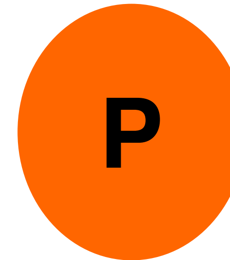
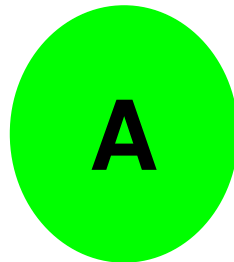
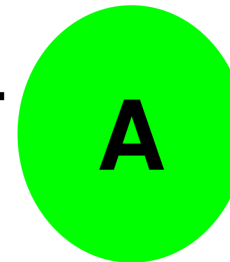
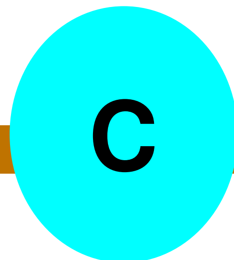
Patient–Therapist–Interaction: constructive

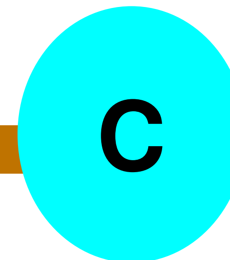
Patient **Therapist**





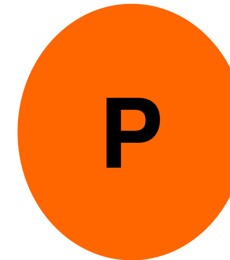


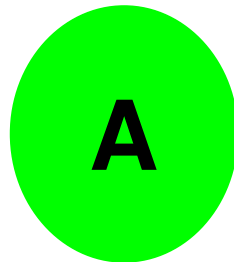


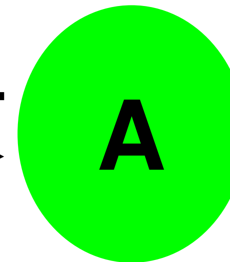


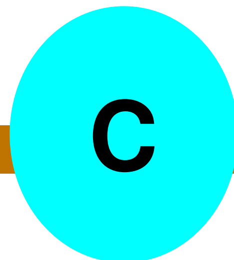
Patient–Therapist–Interaction: constructive

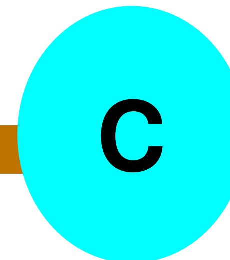
Patient **Therapist**











Advice – home work

Ask your next 3 „chronic" patients about their hobbies and resources?

Check the effects of your intervention.

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Individualized rehabilitation in chronic patients

- Relationship
  - between patient and his problem
  - between therapist and patient
- Set attractive goals to activate resources
- Focus on the patient as a person including problems, resources and many other aspects