



shared  
decision making

*Partizipative Entscheidungsfindung*

# A modular approach in the development and implementation of a decision support tool for patients with schizophrenia

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# Introduction

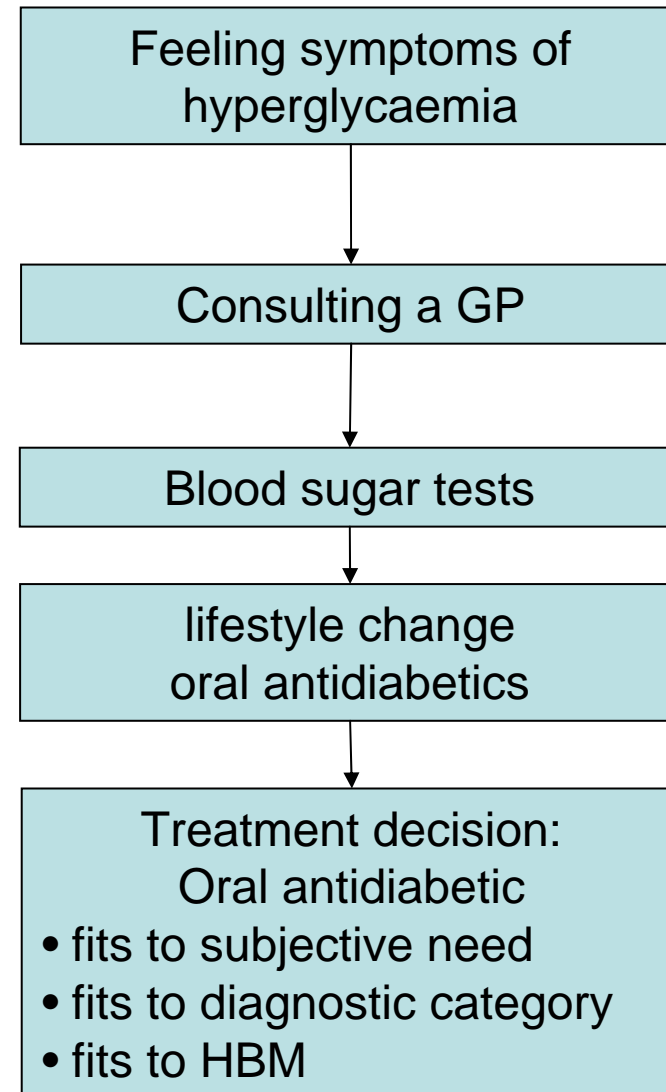
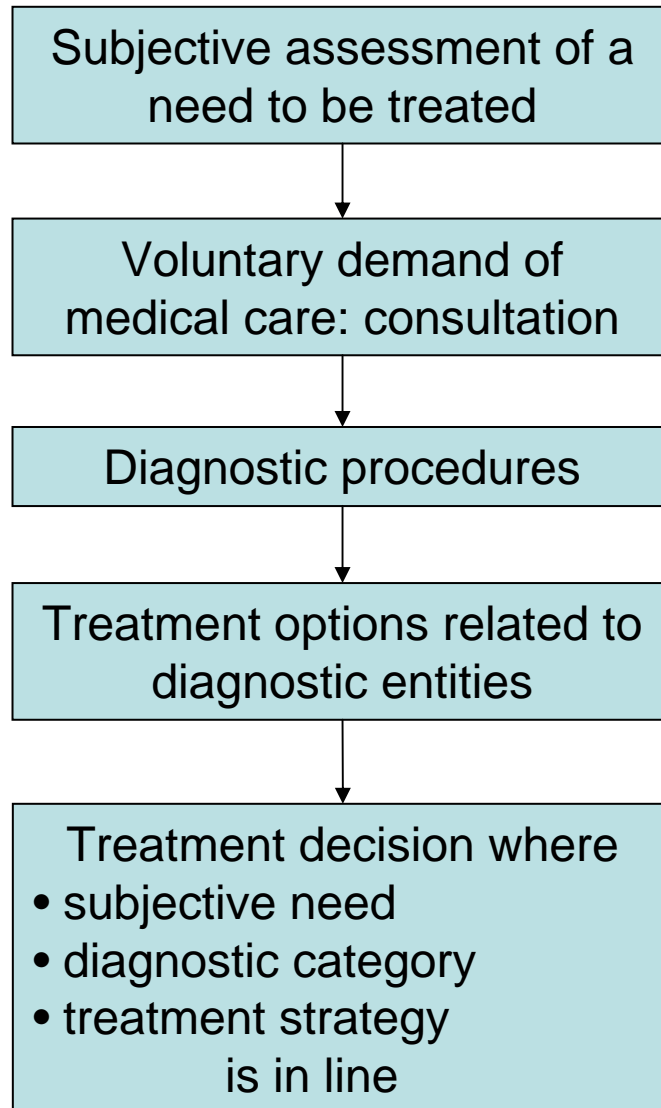
## Feasibility of SDM in medical care of schizophrenia

- multiple evidence based treatment options are available
- multiple decisions at different stages of the treatment
- patients' interest and ability

## Research results

- effectiveness of SDM in schizophrenia care is unclear
- patients demonstrate a lack of treatment acceptance and insufficient adherence

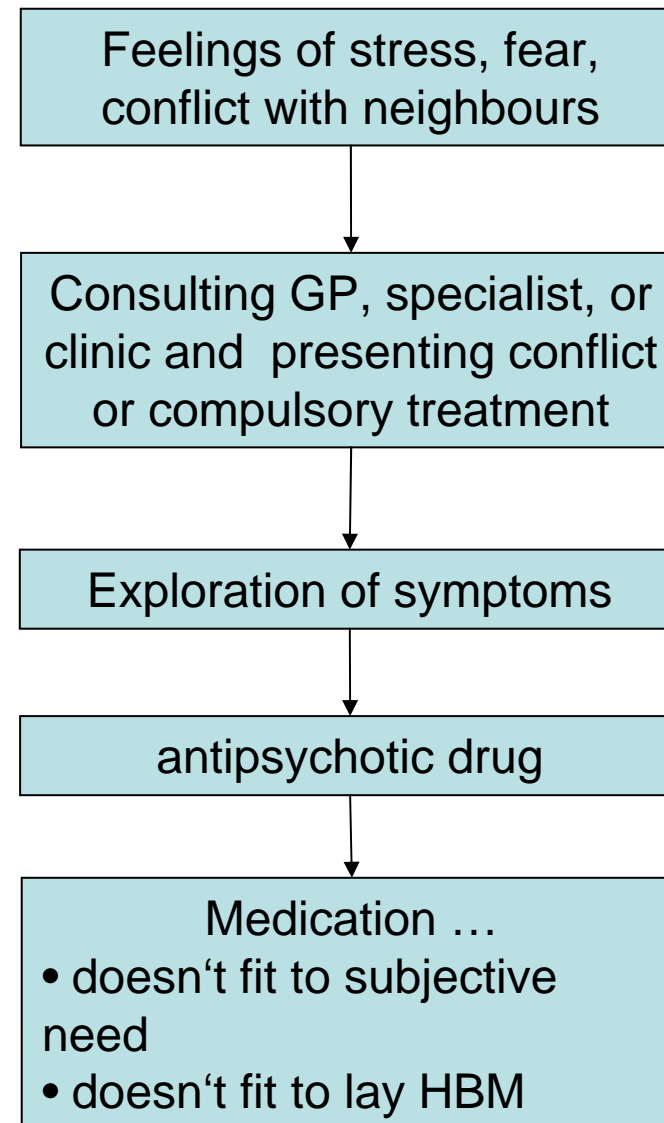
# Procedures of a decision making process in a somatic disease

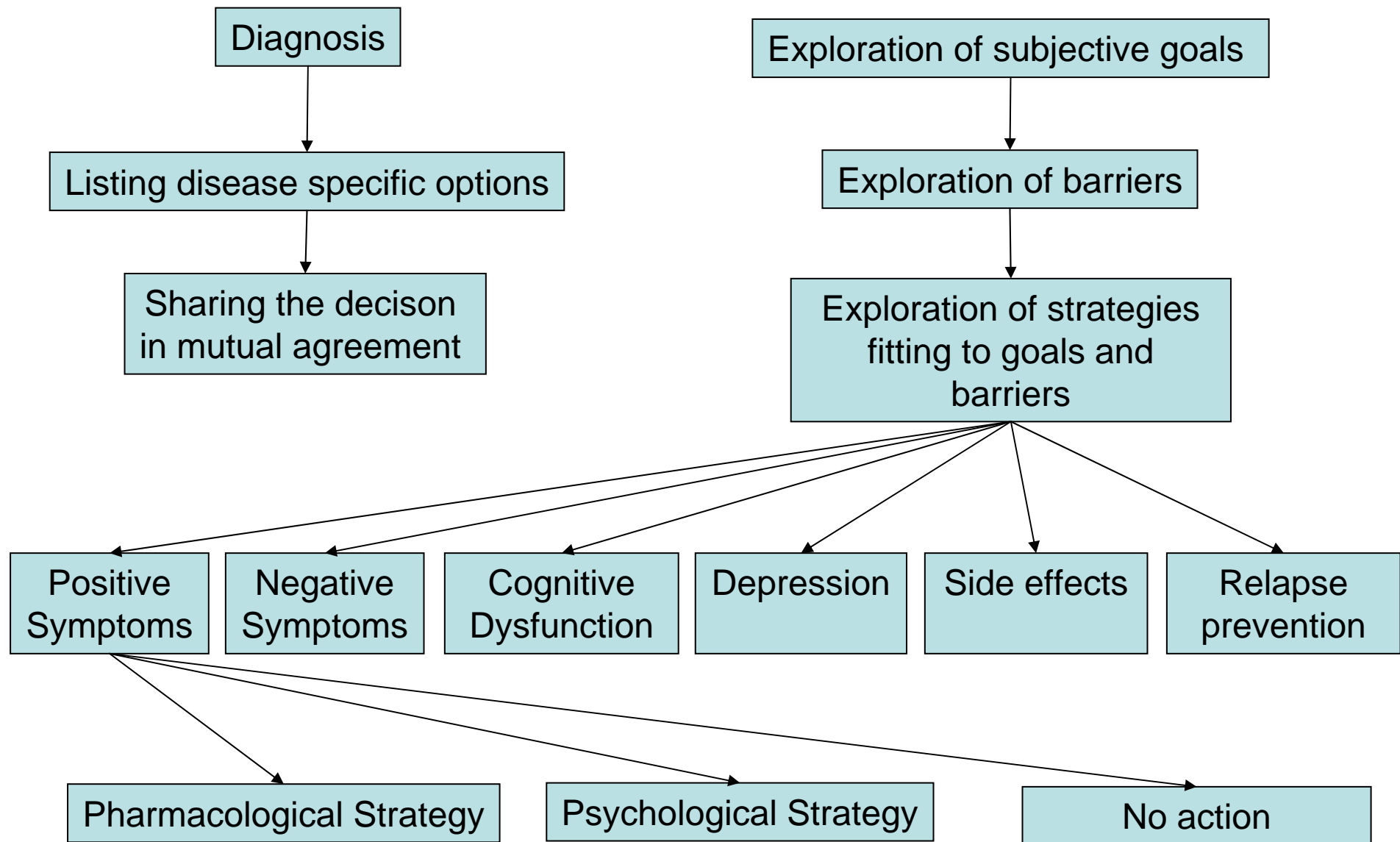


In contrast in schizophrenia frequently ...

- there is no subjective need to be treated
- patients have no insight, no patient role
- treatment is not a goal in itself
- no voluntary access to medical system or physician
- introspection, goal orientation, and (cognitive) focussing (medical) content is impaired by schizophrenia
- previous negative experiences (compulsive treatments)

In contrast an example  
for a decision making  
process in  
schizophrenia





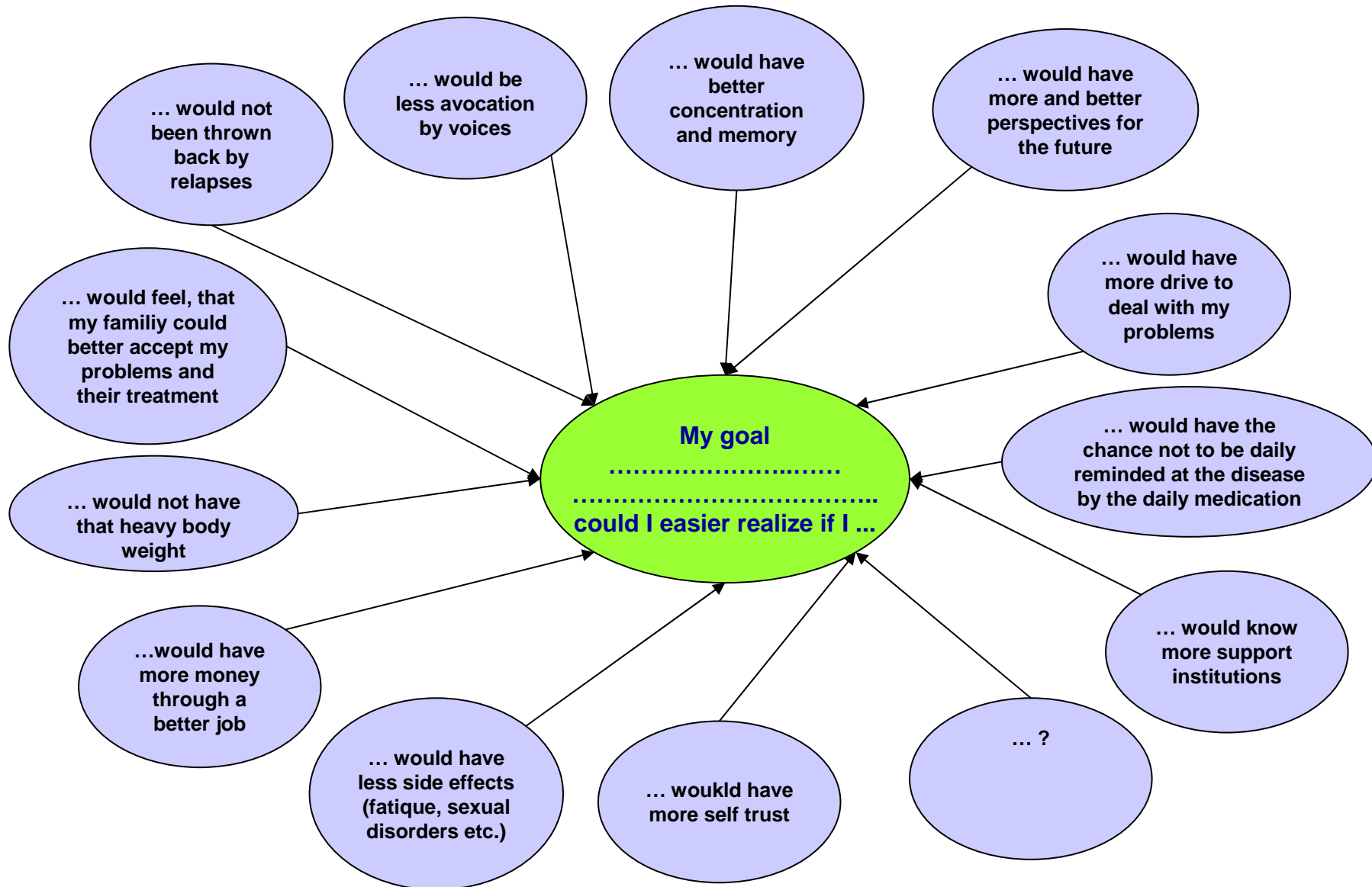
## Module working with goals

### What do I want - finding my aims – a menu of goals



# Module Barrier Analysis

Finding out what hinders me – a „menue“ of barriers



e.g. Module  
Positive  
Symptoms

**My goal: Having better ability to plan all day life (e.g. better contact with my family, less fears, less confusion, no more voices ...)**

**1. Pharmacological strategies**

**2. Psychological strategies**

**3. No action / no change**

**Continuously taking medication**

**Pros:**  
Reduces ...  
• symptoms  
• risc for substance abuse, behaviour deviations, delinquency, aggression etc.  
•demand of emergency units

Improves ...  
• psychosocial functioning  
• cognitive functioning  
• Quality of life

**Cons:**  
• ev. side effects  
• feeling not being able to overcome the disease  
• fear of losing control over self and future  
• fear against stigmatization

**Higher dose, medication change, multiple substance combination**

**Pros:**  
• better efficacy  
• reaching efficacy by reduced side effects

**Cons:**  
• ev. more side effects  
• lack of knowledge in consequences of combined treatments

**Depot medication instead of oral**

**Pros:**  
• proven efficacy  
• no need for daily intake

**Cons:**  
• fear towards side effects  
• anxiety against injections  
• fear of losing control over treatment  
• feeling that physician mistrusts patient  
• losing awareness of beeing responsible

**Working with (confronting) self perceptions, learning to cope better with voices, behaviour therapy**

**Pros:**  
• reduces burden by symptoms  
• improved control over disease or symptoms

**Cons:**  
• emotional risc (by developing a sign. relationship to the therapist)  
• fear that symptoms may increase while talking about them

**Learning to go without drugs (e.g. cannabis, alcohol)  
• cognitive behaviour therapy  
• motivational interviewing**

**Pros:**  
• To develop a consciousness for problems  
• Learning to assess drug consumption in regard to their own aims  
• To compile strategies for being abstinent  
• Learning to deal with relapse

**Cons:**  
• High expenditure of time  
• Being confronted with triggers for drug consumption  
• confrontation with failure  
• group situation

**Pros:**  
• No adverse effects  
• No expenditure of time

**Cons:**  
• Frequently negative affects (anxiety and depression)  
• social retirement  
• limitation of quality of life  
• stress for the family  
• social and occupational drawback  
• suicide risk

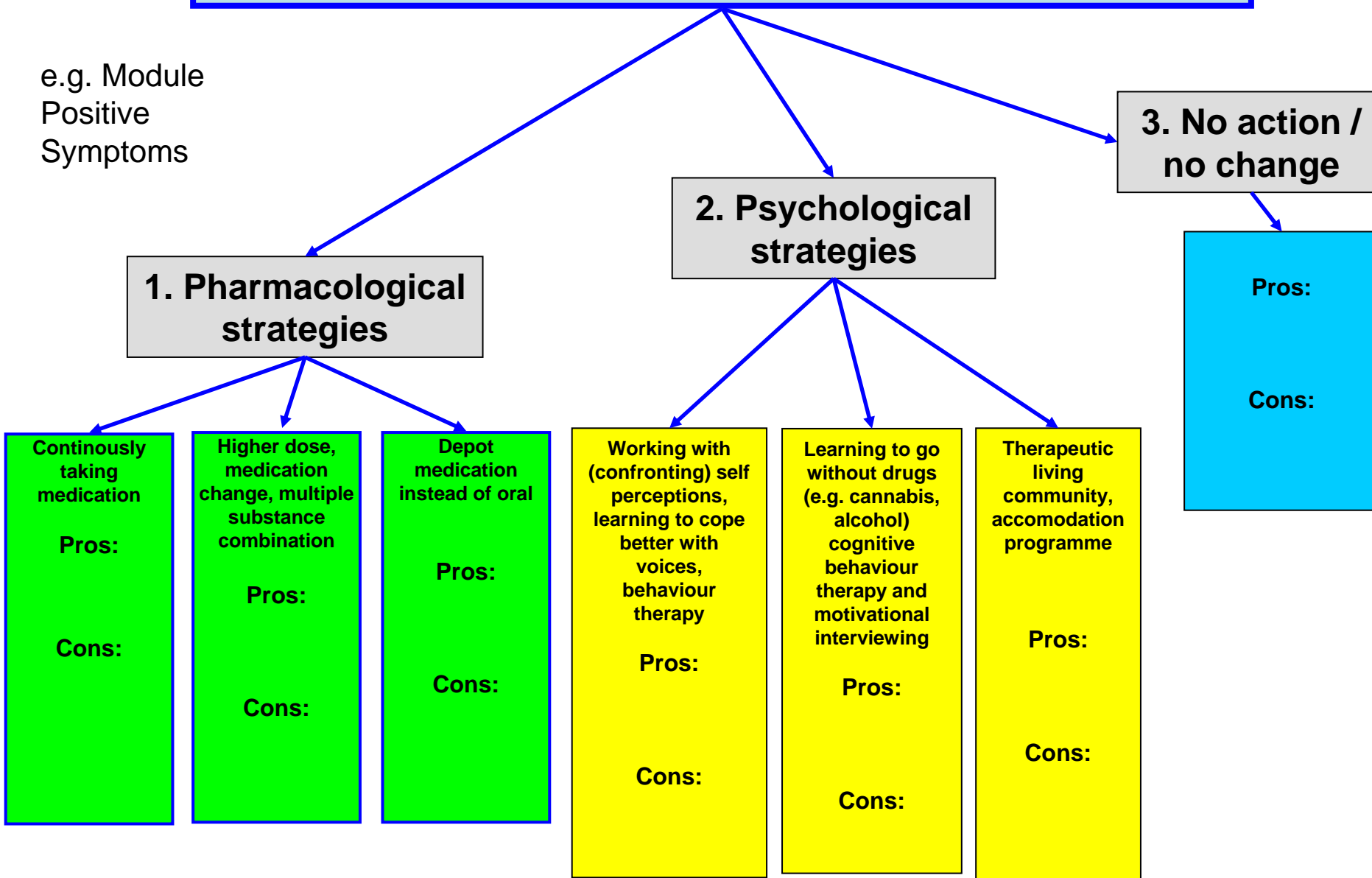
**Therapeutic living community (accomodation programme)**

**Pros:**  
• lower effort  
• facilitation of social contacts  
• to avoid situations of ensnarement  
• help with taking medicaments

**Cons:**  
• abdication of autonomy which would be in an own flat

**My goal: less uncertainty, less anxiety, being less absorbed, less voices:  
The strategies would have the following Pros and Cons for my all day life:**

e.g. Module  
Positive  
Symptoms



# e.g. Module Positive Symptoms

Uncertainty, anxiety,  
hearing voices  
reduced by:

- Improvement of medical treatment
- Psychological strategies
- waiting and observing

**Waiting and Observing**

Pros:

Cons:

**Learn to check estimations, learn to deal with hearing voices, behaviour therapy**

Pros:

Cons:

**Taking medications continuously**

Pros:

Cons:

**Depot medication instead of oral**

Pros:

Cons:

**Therapeutic accomodation - programmes**

Chancen:

Risiken:

**Learning to go without drugs (e.g. cannabis, alcohol)**

**cognitive behaviour therapy and motivational interviewing**

Pros:

Cons:

**Higher dose, medication change, multiple substance combination**

Pros:

Cons:

e.g. Module  
Cognitive  
Dysfunction

**My aim: improving cognitive capacity, better participation  
in life, better job chances by ...**

**1. Improvement of  
medical treatment**

**Medication adjustment /  
combination**

**Pros:**

- More efficiency by changing therapy to atypics

**Cons:**

- Possibly increasing of adverse effects
- Less knowledge about safety with combination therapy

**2. Psychological  
strategies**

**Cognitive remediation**

**Pros:**

- More efficiency
- well effects on occupational integration

**Cons:**

- expenditure of time

**Improving cognition by  
communication - training**

**Pros:**

- Improving talking to friends and colleagues
- becoming more self confident

**Cons**

- expenditure of time
- uncertainty caused by group situation

**3. No action, treatment  
and non or poor  
compliance like before**

**Pros:**

- No adverse effects
- No expenditure of time
- No uncertainty by adjustment

**Cons:**

- impairment caused by cognitive functional disorder
- impairment of social and occupational integration
- response on psychosocial interventions reduced

e.g. Module  
Cognitive  
Dysfunction

**My aim: Improved concentration, better participation in life,  
enhanced cognitive capability:  
The strategies would have the following Pros and Cons for my all  
day life:**

**1. Improvement of  
medical treatment**

**Mdication adjustment /  
combination**

**Pros:**

- 
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- 
- 

**Cons:**

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- 

**2. Psychological  
strategies**

**Cognitive remediation**

**Pros:**

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**Cons:**

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**3. No action, treatment and  
non or poor compliance like  
before**

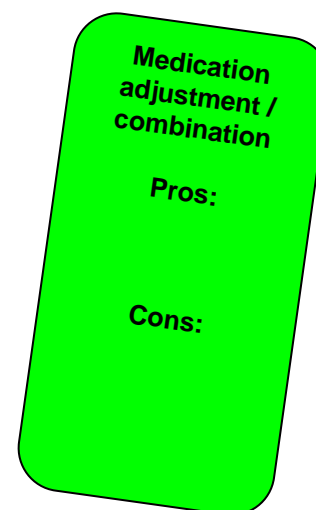
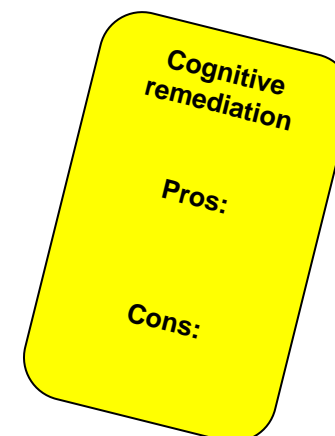
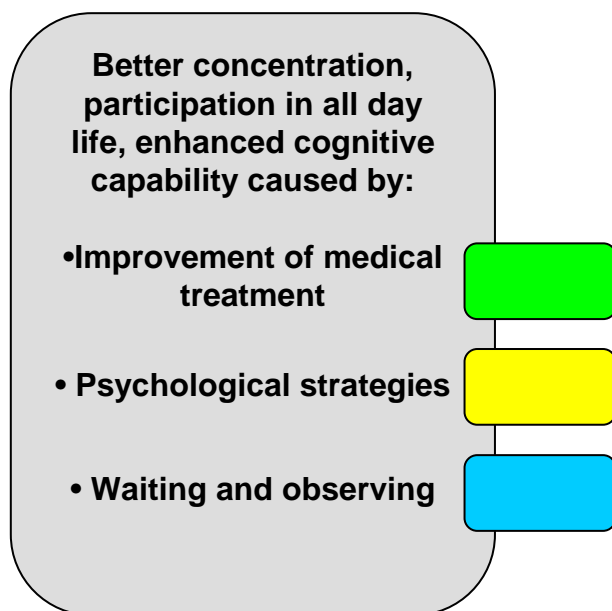
**Pros:**

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- 
- 
- 

**Cons:**

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- 
- 
-

e.g. Module  
Cognitive  
Dysfunction



Module  
Relapse  
prevention

**My aim: living uninfluenced by illness,  
avoiding relapses**

**1. Improvement of  
prophylaxis medicaments  
to avoid relapses**

**3. Waiting and observing**

**Go on with taking medication instead of finishing treatment**

**Pros:**

- Reduces ...
- Risk for relapse and necessity for hospitalization
- bad psychosocial functional level (social, occupational integration, all day life competences)
- higher risk for drug and alcohol abuse, delinquency and aggressive attitudes
- usage of emergency units
- cognitive drawback

Improves ...

- quality of life

**Cons:**

- Adverse effects
- feeling to can not getting over the illness
- fear for loss control of future
- fear for stigma

**Higher dose, medication change**

**Pros:**

- Well compound of safety and adverse effects

**Cons:**

- Increasing of side effects
- less knowledge about safety of combination medicaments
- Psychological uncertainty caused by alteration

**Depot instead of oral dosage**

**Pros:**

- No thinking about medication, no problems of oblivion
- No embarrassment by taking medication in public (in free time, with friends)
- In part less adverse effects

**Cons:**

- fear for injection – pain
- fear for loss controlroll
- Feeling mistrusted and aggrieved
- Feeling not as an adult by loosing responsibility

**2. Psychological improvement of relapse prophylaxis**

**Pros:**

- No adverse effects of medication
- No expenditure of time
- No stress caused by the group

**Cons:**

- Often relapses
- Rehospitalization often necessary
- Repeated relapses could produce resistance in treatments in the future
- Maybe changes of brain morphology caused by relapses
- Loss of self-worth (feeling of being the puppet of their illness)

**To develop early warn signals and an emergency plan (inclusion of family and friends)**

**Pros:**

- Reduces risk for relapse and necessity for hospitalization
- Low expenditure of time

**Cons:**

- As sole method unsafe

**Improving regulation of stress**

**Pros:**

- Reduces the feasibility of relapses
- Reduces time of hospitalization
- Improving of strategies for problem and conflict solutions in family

**Cons:**

- High expenditure of time
- Confrontation with stress and conflicts could be temporary more stressful

**Improving emotional mood in the family**

**Pros:**

- Reduces negative criticism
- Lowers family stress (family members might interact stressfully; emotional overengagement, fear of loss of control)
- Reduces relapses and rehospitalizations
- Ev. improvement of role functions

**Cons:**

- High expenditure of time
- Maybe lacking adherence of relevant members
- Confrontation with stress and conflicts is temporary more stressful

**Ability to be abstinent of relapse provoking drugs**

**Pros:**

- Learning to reflect the aims of drug consumption
- To compile strategies for being abstinent

**Cons:**

- High expenditure of time
- Being confronted with triggers for drug consumption (group situation)

Module  
Relapse  
prevention

**My aim: living uninfluenced by illness;  
avoiding relapses: The strategies would have  
the following Pros and Cons for my all day life**

**3. Waiting and observing  
(only consultations at  
regular intervals and  
restart of treatment in  
case of relapse - signals)**

**Pros:**  
  
**Cons:**

**1. Improvement of  
prophylaxis medicaments  
to avoid relapses**

**2. Psychological  
improvement of relapse  
prophylaxis**

**Go on with  
taking  
medication  
instead of  
finishing  
treatment**

**Pros:**

**Cons:**

**Higher dose,  
medication  
change**

**Pros:**

**Cons:**

**Depot  
instead of  
oral dosage**

**Pros:**

**Cons:**

**To develop early  
warn signals  
and an  
emergency plan  
(inclusion of  
family and  
friends)**

**Pros:**

**Cons:**

**Improving  
regulation of  
stress**

**Pros:**

**Cons:**

**Improving  
emotional  
mood in the  
family**

**Pros:**

**Cons:**

**Ability to be  
abstinent of  
relapse  
provocating  
drugs**

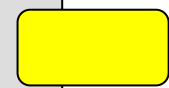
**Pros:**

**Cons:**

# Module Relapse prevention

Living uninfluenced of illness, avoiding relapses by:

- Improvement of prophylaxis medicaments to avoid relapses
- Psychological improvement of relapse prophylaxis
- Waiting and observing (only consultations at regular intervals and restart of treatment in case of relapse - signals)



To develop early warn signals and an emergency plan (inclusion of family and friends)

Pros:

Cons:

Waiting and observing (only consultations at regular intervals and restart of treatment in case of relapse - signals)

Pros:

Cons:

Improving emotional mood in the family

Pros:

Cons:

Go on with taking medication instead of finishing treatment

Pros:

Cons:

Improving regulation of stress

Pros:

Cons:

Depot instead oral dosage

Pros:

Cons:

Ability to be abstinent of relapse provoking drugs

Pros:

Cons:

Higher dose, medication change

Pros:

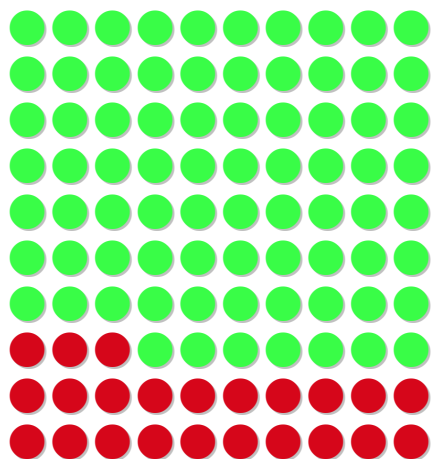
Cons:

# Developing treatment acceptance

The patient evaluates:  
What will be my contribution to avoid a relapse?

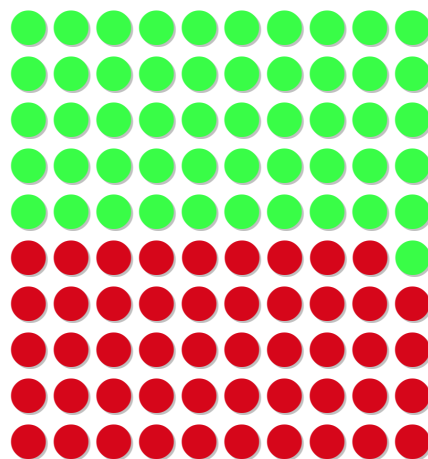
● No relapse

● Relapse



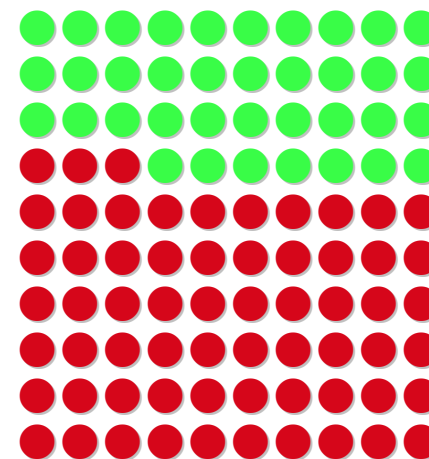
Uninterrupted therapy

23 % Relapse



Therapy in case of early warning signals

49 % Relapse



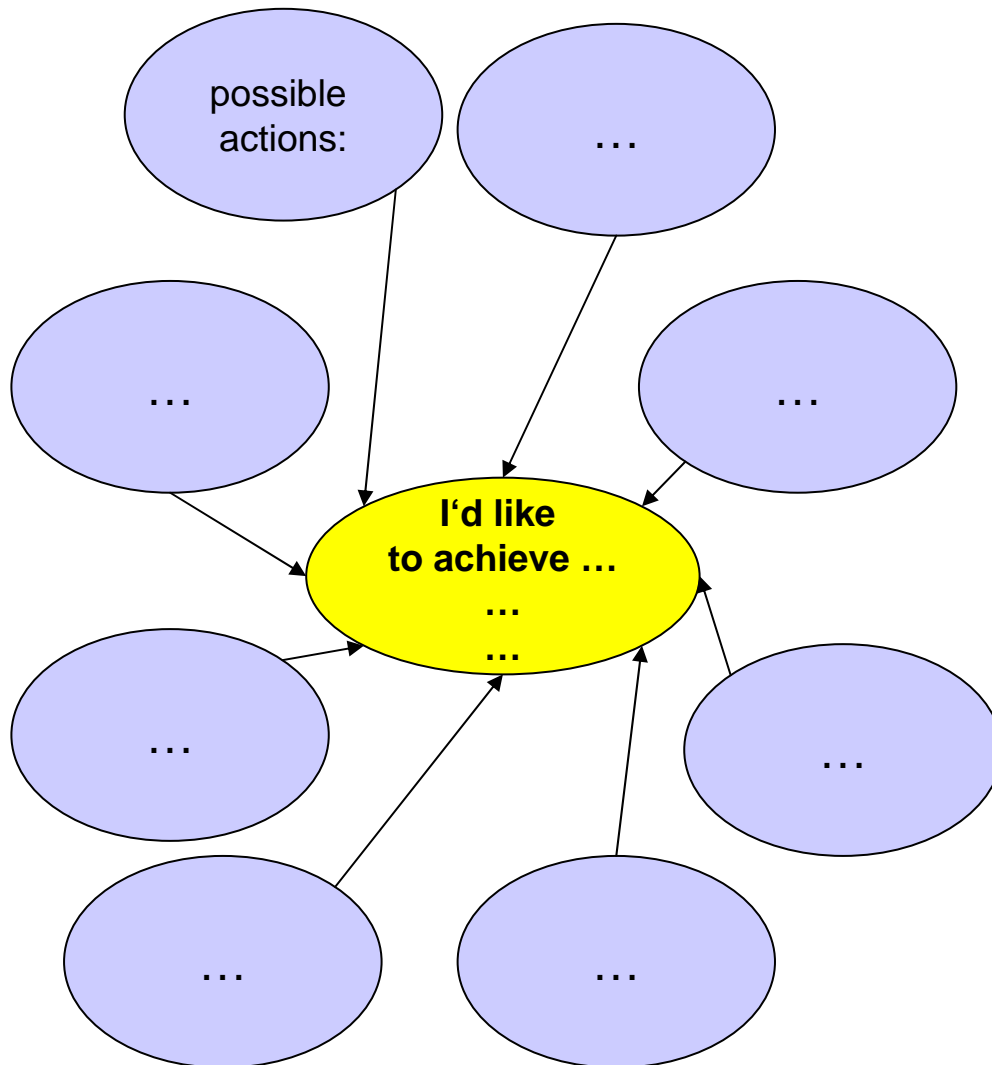
Therapy in case of beginning crisis

63 % Relapse

# Module: Aims of treatment



**Record sheet:** Recognition makes it easier....



**My preferences:**  
Aims in order of importance:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

**Steps on the path to my aims:**  
What are the most important steps on my way to the named aims?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Personal criteria for success:**  
What are the signs to realize that I approximate my aim?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## SDM – concepts in schizophrenia require ...

- an integration of goal and barrier modules
- usage of different target modules
  - Positive Symptoms
  - Negative Symptoms
  - Cognitive Dysfunction
  - Depression
  - Side effects
  - Relapse Prevention
- close association between modes of action (therapy) and aims
- presenting collected individual criteria before decision making
- trade off in handling visualizations (card sorting method)

# Conclusion

- Concept is challenging but meaningful
- Material is quite expensive
- First evaluations show: trained clinicians evaluate the concept feasible and effective

Thanks you for your attention !



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