

MENTAL HEALTH, PSYCHE, BREATHING

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Psychologist
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Psyche & AATD

- ❖ Reduced capacity, Limitations in everyday life
- ❖ Uncertainty and fears about the future --> unpredictable course of the disease
- ❖ Financial problems due to reduced ability to work
- ❖ Concerns about genetic transmission
- ❖ Prolonged suffering before diagnosis, lack of awareness of the disease

Beiko & Strange 2019

- ❖ Quality of life is only indirectly related to the physical condition (lung function...)
- ❖ Impact of mental stress significantly higher

Brien et al. 2016

Prevalence of clinically relevant psychiatric syndrome

16 % (Mobeen et al. 2021) –
31 % (Greulich et al. 2017)

- ➔ Anxiety
- ➔ Depression



Relationship between Depression and Anxiety, Health Status and Lung Function in Patients with Alpha-1 Antitrypsin Deficiency

Farah Mobeen^{a,b}, Ross G. Edgar^{b,c} , Anita Pye^b , Robert A. Stockley^a, and Alice M. Turner^{b,d} 

Monitoring Mental Health:

Actively in medical routine

- ➔ High prevalence
- ➔ Significant impact on quality of life and treatment adherence

Holistic Treatment Approaches:

integrating psychological assessments and treatments into the care plan for AATD patients to improve overall health outcomes and reduce hospitalizations and mortality rates

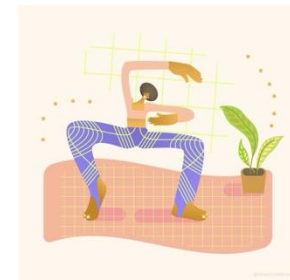


Education and rehabilitation
To manage disease and mental stress.



Cognitive Behavioral Therapy (CBT):
Managing anxiety, „Unlearning“ anxiety




Pacing (managing energy/ effort over time)



Relaxation and mindfulness:
Improves anxiety and depression, physical performance, quality of life
QiGong: Wu, J. *et al.* (2019).
Tai Chi: Guo, C. *et al.* (2020).
Yoga: Cramer, H. *et al.* (2019).



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In the [...] cohort **depression/anxiety** was linked to a **greater decline in FEV1**

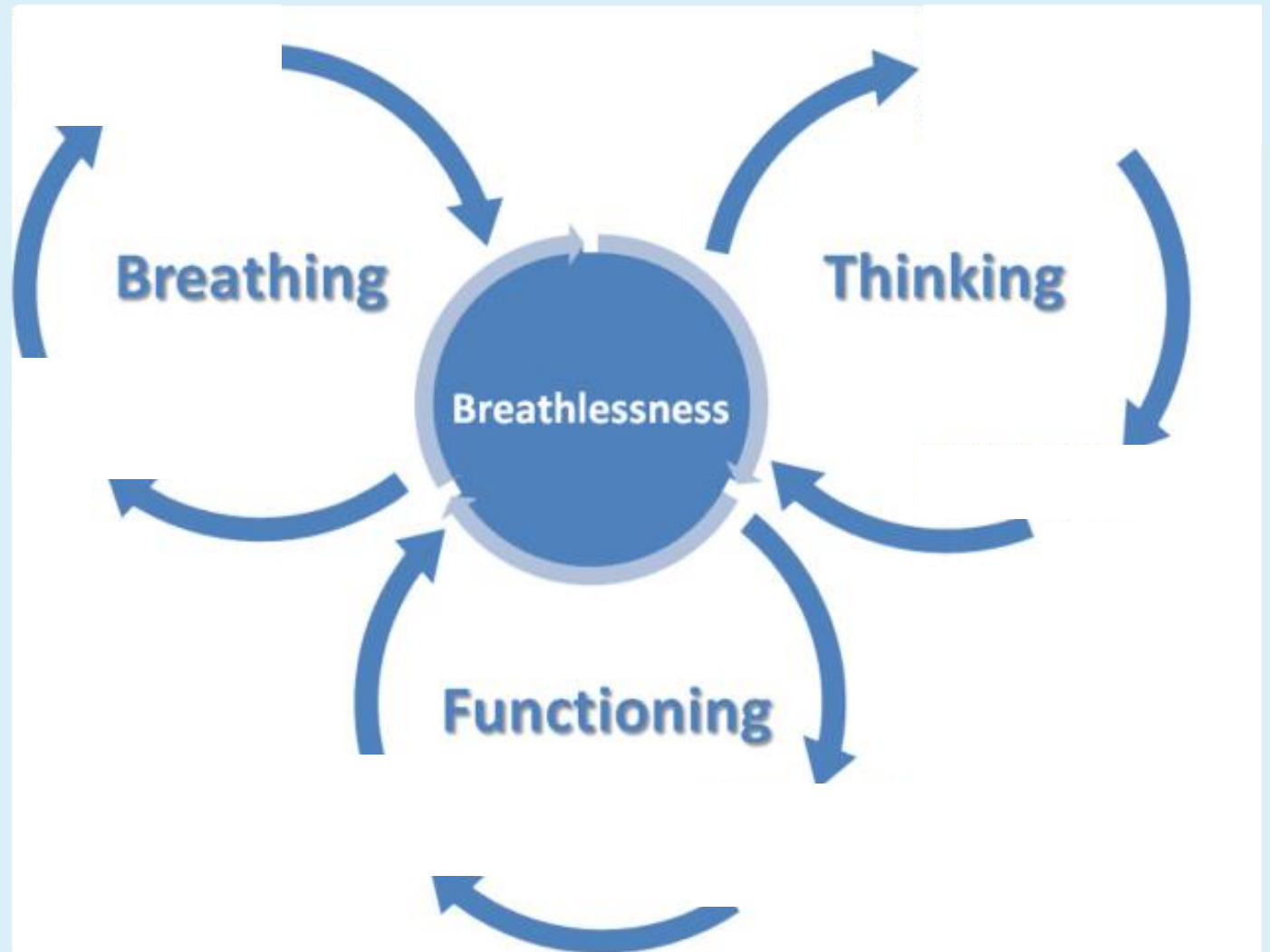
Breathing – Thinking – Functioning Model Spathis et al. 2017

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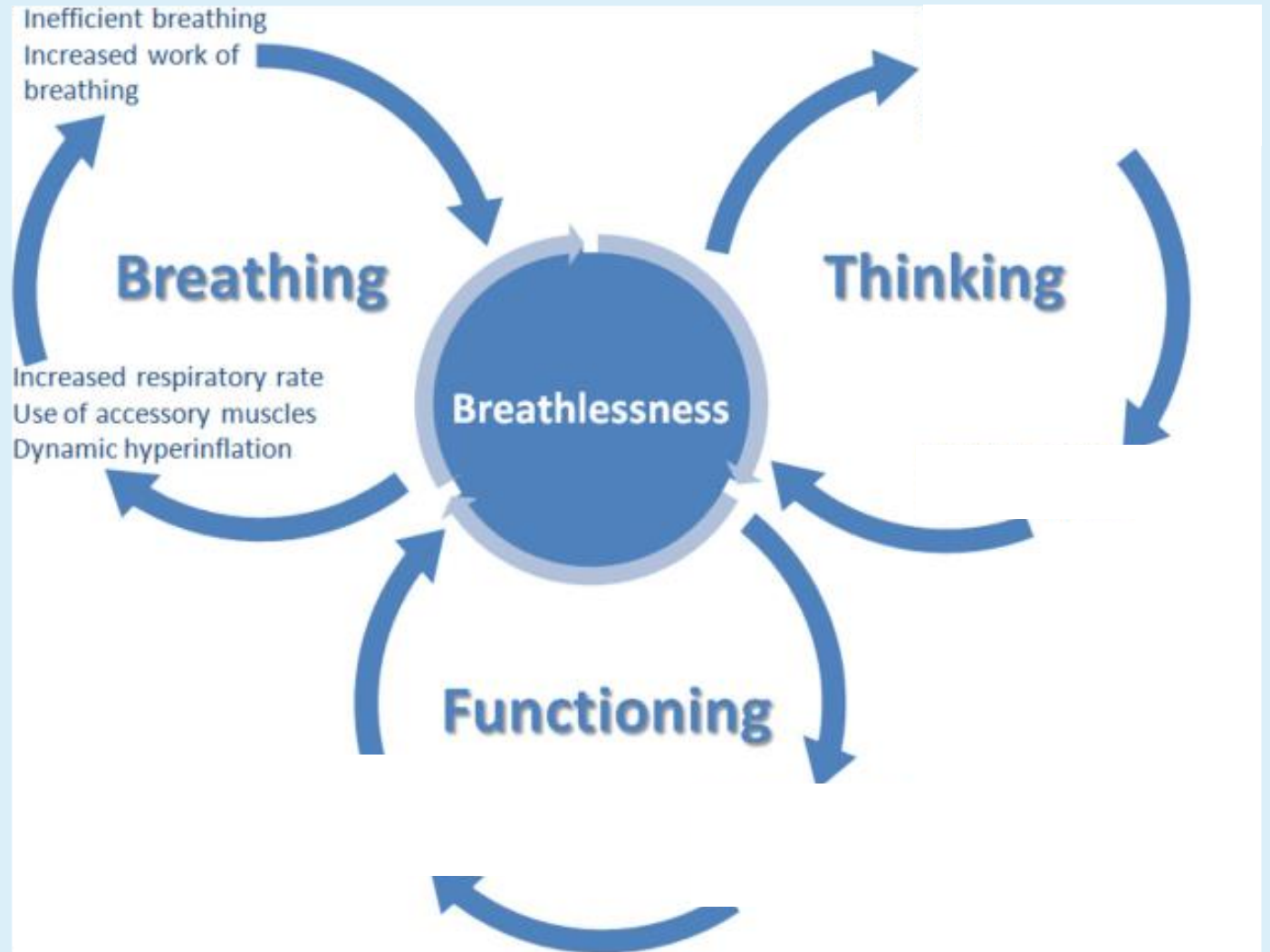
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Symptom management approaches

Spathis et al. 2017

Breathing:

- ❖ Breathing techniques
- ❖ Handheld fan
- ❖ Inspiratory muscle training
- ❖ Non-invasive ventilation

„It is natural to think when you are feeling breathless that you need more air in. In fact this isn't the case -we know that there is plenty of air in your lungs. Try instead to lengthen your out breath, which can make your breathing more efficient and create space for your next breath.“

Spathis et al. 2017, p. 5

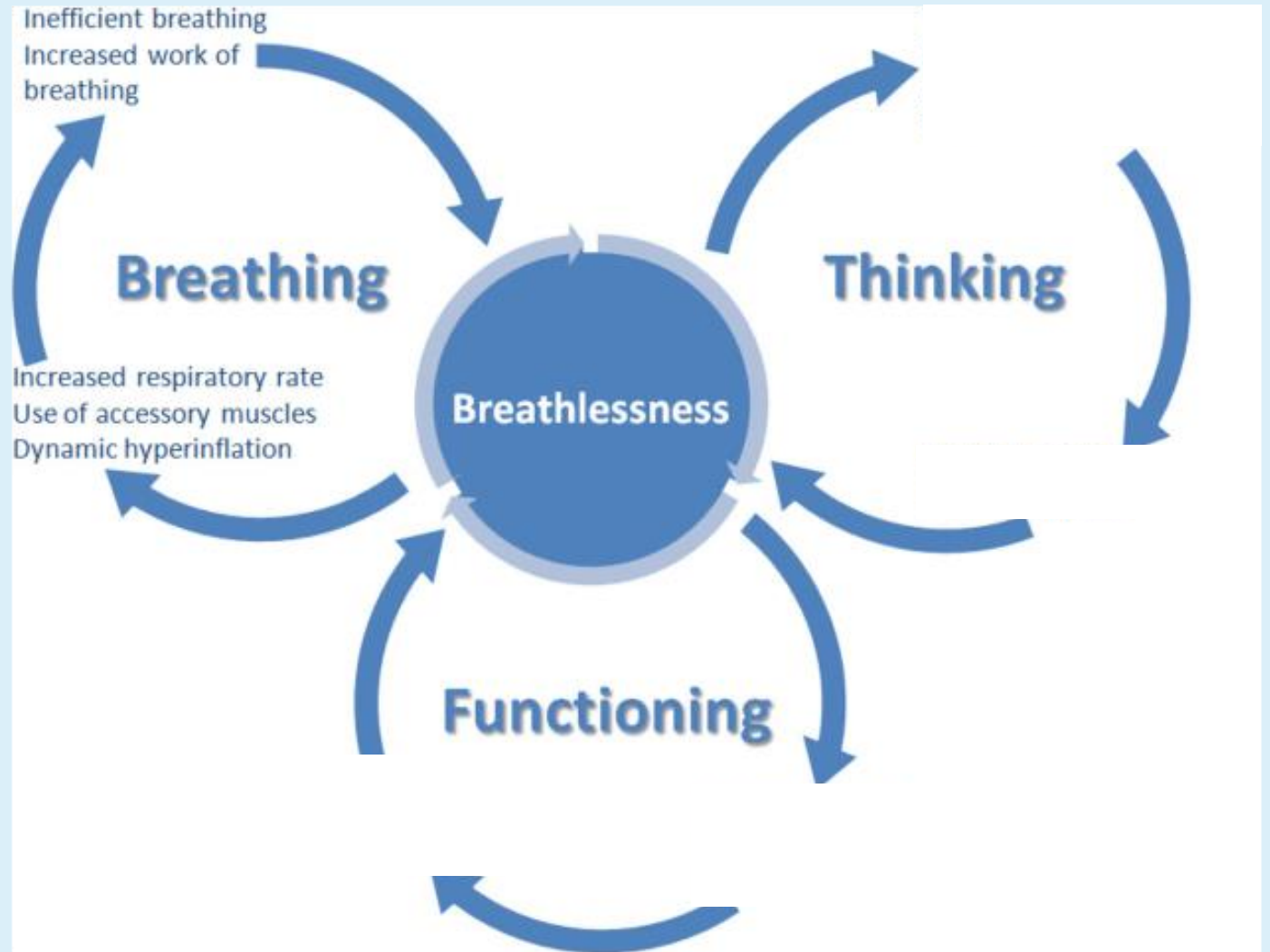
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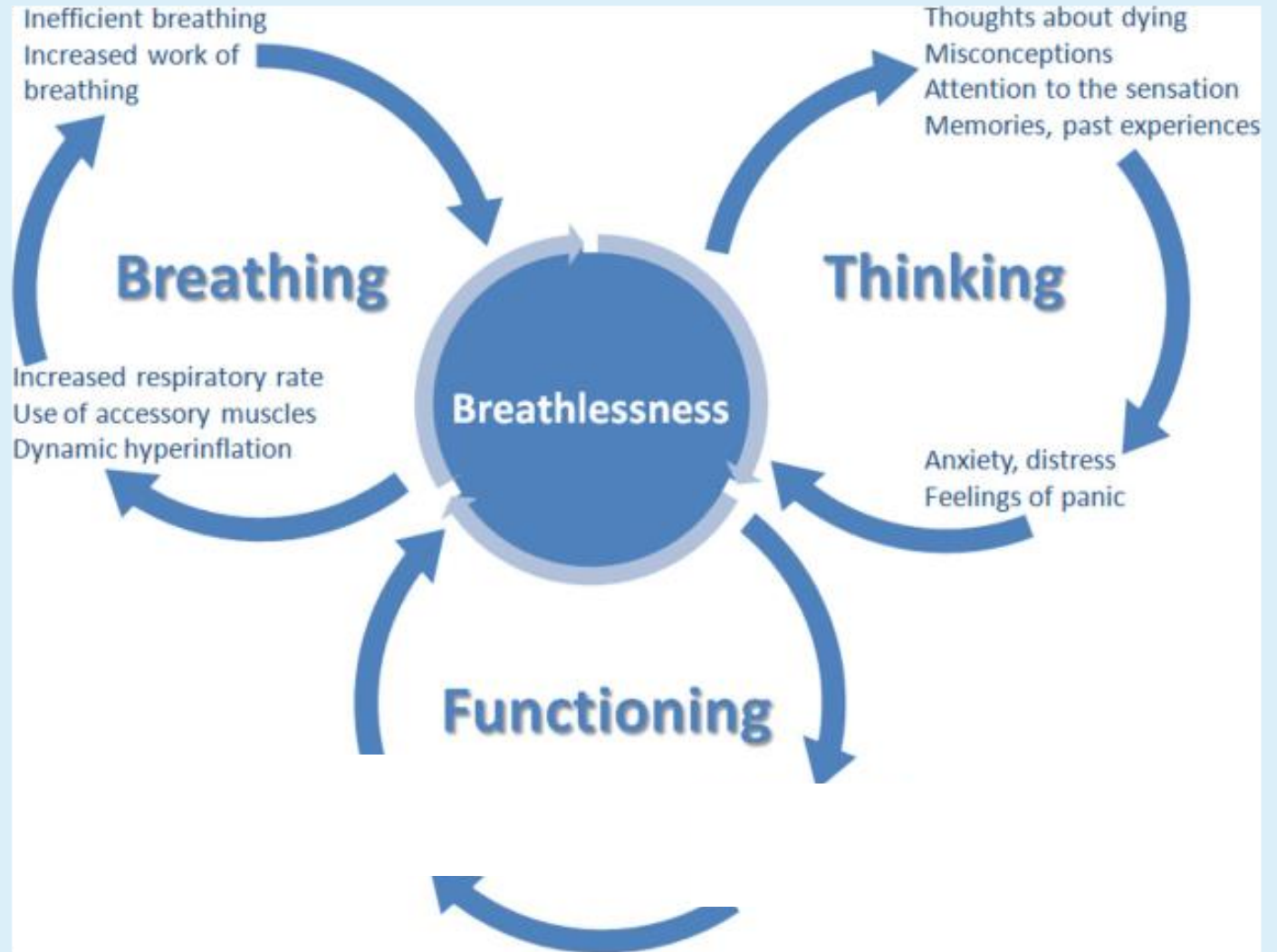
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Symptom management approaches

Spathis et al. 2017

Thinking:

- ❖ Cognitive behavioral therapy
- ❖ Relaxation techniques (PMR; AT; ...)
- ❖ Mindfulness

"Some people say that they're terrified that they are going to die gasping for breath. Although this is an understandable feeling, this almost never happens - At that time, waste gases tend to build up in the blood, making people feel calm and sleepy."

Spathis et al. 2017, p. 5

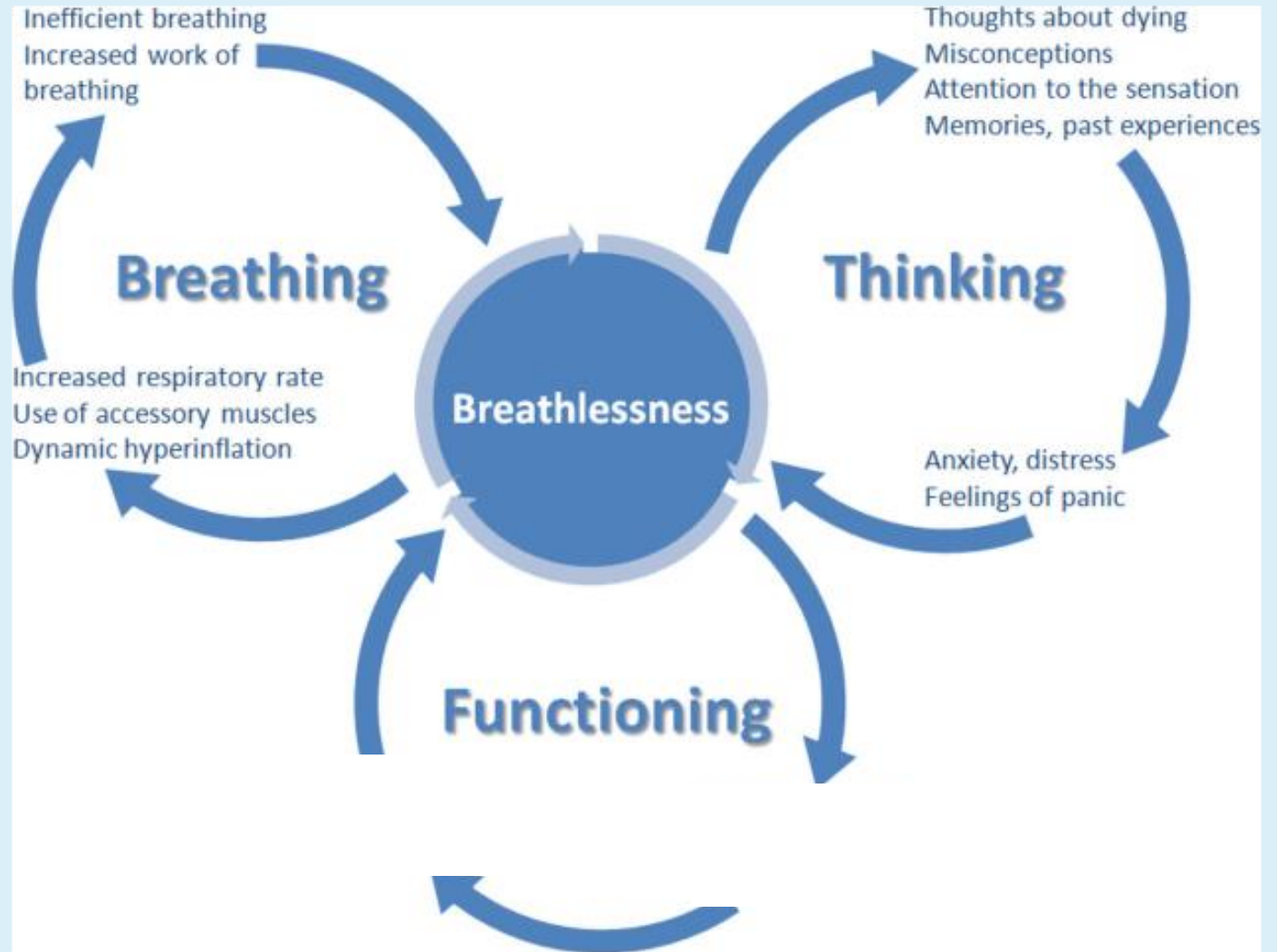
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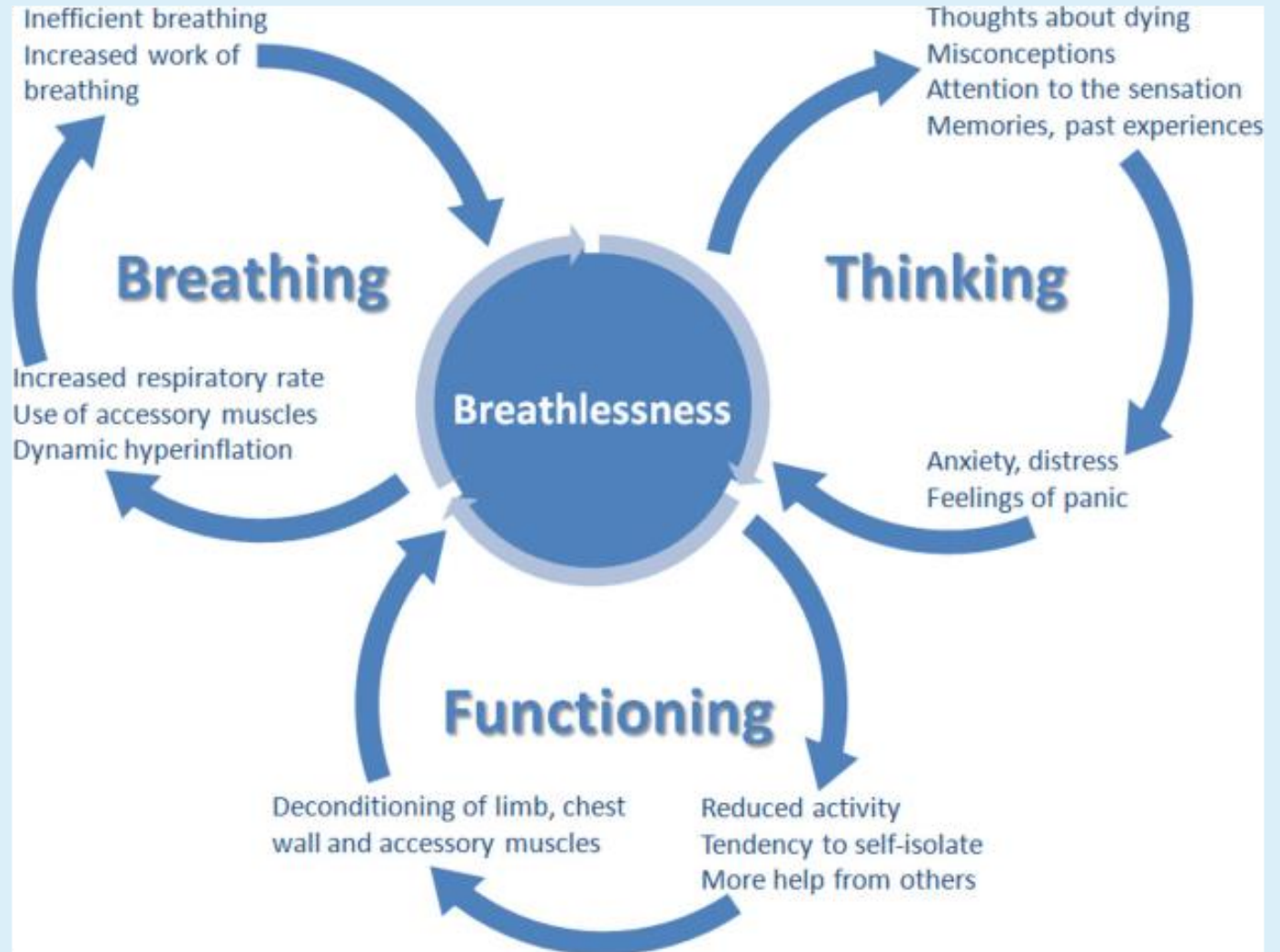
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Symptom management approaches

Spathis et al. 2017

Functioning:

- ❖ Pulmonary rehabilitation
- ❖ Pacing
- ❖ Walking aids

"Choosing to make yourself moderately breathless by being active is not harming you. In fact it builds up fitness in your muscles again and can improve your breathing and general health over weeks and months."

Spathis et al. 2017, p. 5

Distress and burden on relatives

Miravittles et al. 2022

- ❖ Loss of flexibility and opportunities in professional and social life due to care
 - ❖ Financial problems
 - ❖ Withdrawal, loneliness
 - ❖ Reduced participation (hobbies, travel, ...)
-
- Anxiety, stress, feelings of despair due to worries about the sick family member
 - Feelings of guilt or fear for future generations

Joint active coping with illness

Krämer & Bengel 2016

- ❖ *Actively and consciously* dealing with the illness
- ❖ Activating social and emotional resources: getting and giving advice, attachment and “belonging” as important basic psychological needs
- ❖ Associated with more mental stability, quality of life compared to “*passive*”, *resigned*, *hopeless coping*



Joint active coping with illness

Krämer & Bengel 2016

Sorensen et al. 2002

Meta-analysis of 78 intervention studies
with family caregivers

Best effects on quality of life and mental
status:

Psychoeducational interventions
(information, training, communication)

Psychotherapeutic interventions (cognitive
behavioral therapy, problem solving,
resource management)



THANK YOU FOR YOUR
ATTENTION



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