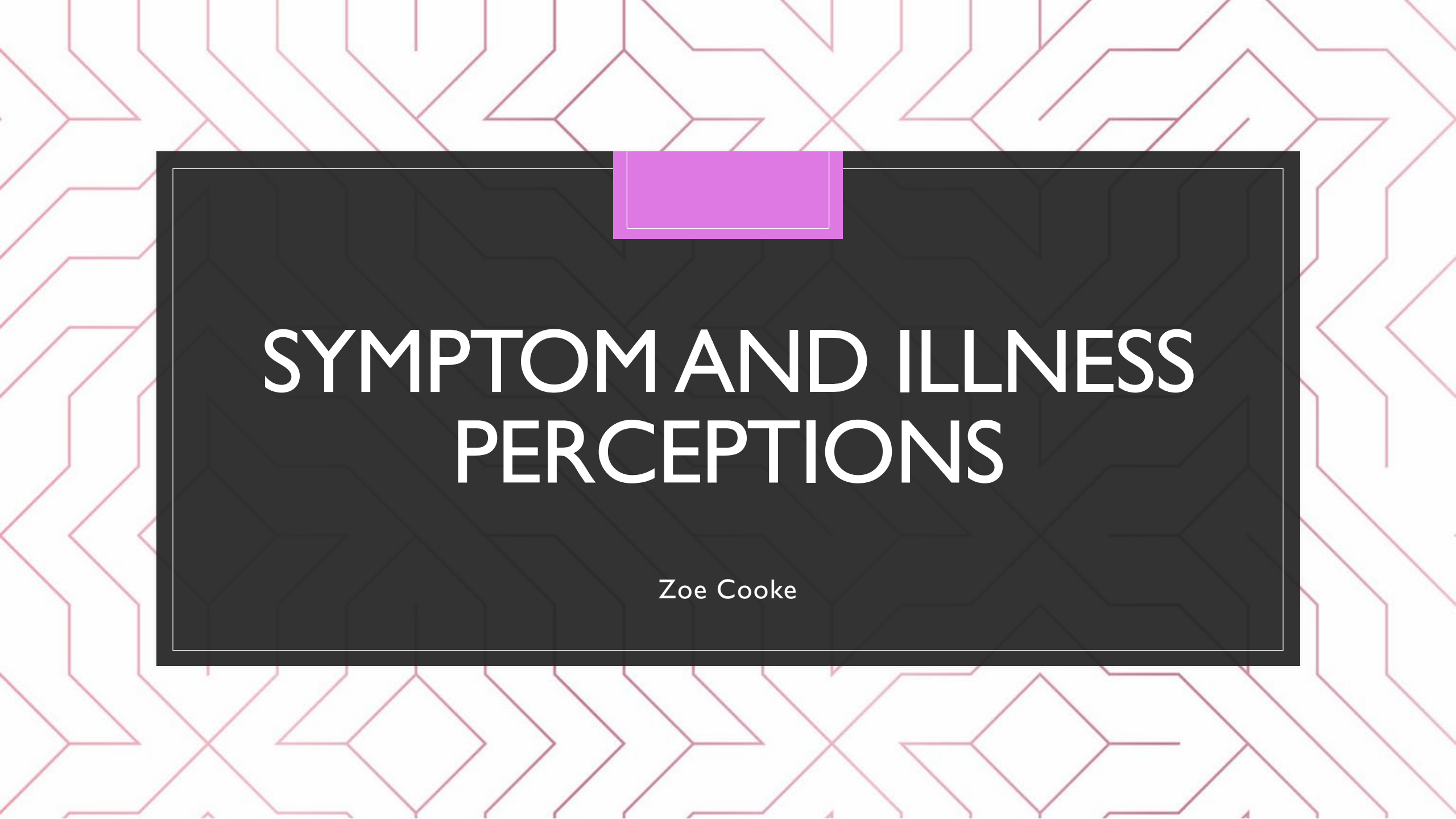


The background of the slide is a light pink color with a repeating geometric pattern of thin, dark pink lines forming various polygons and star-like shapes. A solid pink rectangle is positioned at the top center of the dark grey box.

SYMPTOM AND ILLNESS PERCEPTIONS

Zoe Cooke

Lecture overview

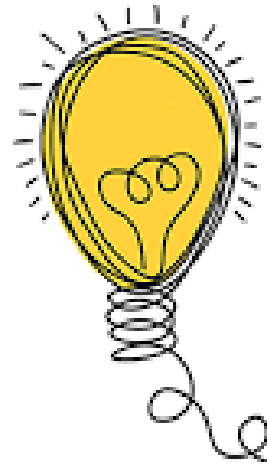
Illness beliefs and perceptions of illness



Self-regulation model



Examples of chronic long-term conditions/diseases and the SRM



What is an illness representation?

Illness representations are an ***individuals' beliefs and expectations about an illness or somatic (physical) symptom***

Leventhal's Self- Regulation Model

- Also known as the Common-sense model of illness
- An alternative way of understanding how people form responses to illness
- Provides a framework for understanding the processes involved in a persons appraisal of health threats
- When applying this model to illness it allows an individual to act as 'common-sense scientists' to manage their condition, make sense of their illness and its associated symptoms and threats (pp.373, Benyamin & Karademas, 2019)
- Adds to Lazarus and Folkman process by adding that there is a direct relationship between illness representations and coping behaviour

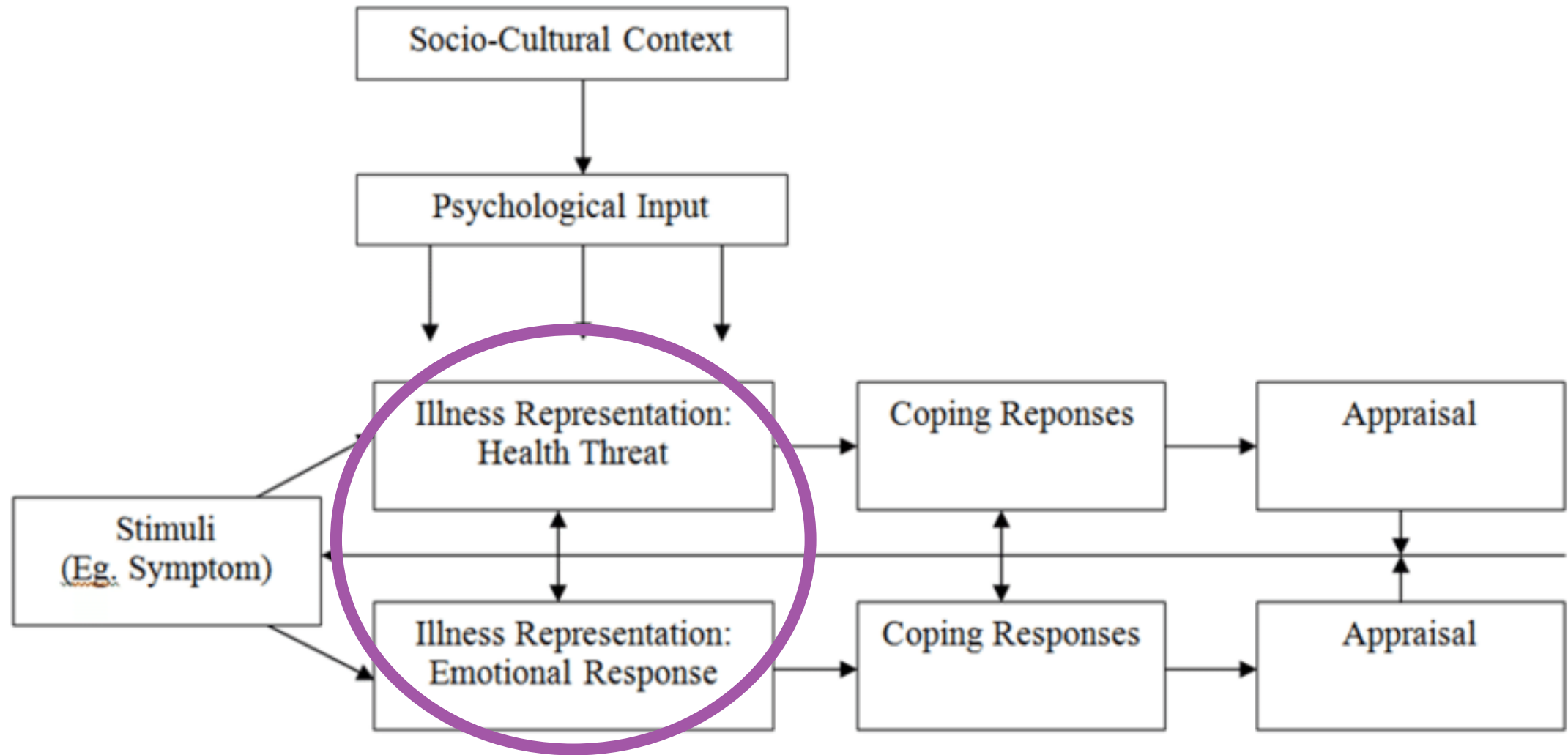
So what?

This model is useful for helping us understand why people make certain decisions.
E.g. why people with lung cancer continue to smoke

By understanding the relationship between illness representations and coping behaviour we can predict adherence to treatment and lifestyle changes

All of these things come hand in hand with health promotion, disease prevention and behaviour change.

This area is focusing on established illness or disease and how we can support those people



Leventhal's Self- Regulation Model

Individuals search to understand their illness or disease by;

- Developing an understanding of what their illness is
- What it means
- Its causes
- Its consequences
- How long it will last
- And whether it can be cured or controlled

This is called their illness representation and may not be scientifically or medically accurate

Illness representations: 5 key dimensions

Identity – the label of the health threat and its symptoms. Signs & symptoms

Cause – individuals' beliefs about the cause of the health threat (genetics, health risk behaviours, fate, accident, infection)

Timeline – the perceived timeframe of disease development, duration, and recovery (Acute, chronic, cyclical)

Consequences – the imagined and real beliefs about what effect the health threat may have on their life

Curability/Controllability – the degree to which someone believes the health threat can be controlled or cured by themselves or others. This later becomes personal and treatment control.

5 key dimensions cont.

- These five dimensions are just the beginning of understanding an individual's response to a health threat
- The perception of a health threat stimulus simultaneously triggers problem-focused self-regulation and emotion-focused self-regulation
 - e.g., physical symptoms or side effects of cancer can initiate feelings of panic or worry (emotional response).
- Being aware of these cues help to activate a help-seeking response
 - (booking a GP appointment or confiding in a friend about the worries).
- The outcome of this process then allows us to see whether the emotional response (panic and worry) has been alleviated by engaging in a help-seeking behaviour.
- If successful, this provides a feedback loop that allows a positive coping response to be formed when faced with another stimulus

Illness representations cont.

Acquired by:

- Media
- Personal experience
- Family and friends

They influence preventative behaviour and coping responses:

- Over/under seeking medical help
- Adherence to treatment (screening, medication)
- Emotional reactions to symptoms (avoidance, hypervigilance)
- Engagement in self-care behaviour

Illness perceptions questionnaire

- Quantitative measure of the five components of illness representations in Leventhal's self-regulatory model.

Scale	Examples of items	Number of items	α^*
Cognitive representations (IPQ-R)			
Timeline	It is likely to be permanent rather than temporary, it will last for a long time	6	0.65 [#]
Timecycle	The symptoms change a great deal from day to day, it is very unpredictable	4	0.61
Consequences	It is a serious condition, it has major consequences on my life	6	0.66 [#]
Personal control	There is a lot which I can do to control it, I have the power to influence it	6	0.73
Treatment control	Treatment will be effective in curing my illness, there is little to be done to improve it (r)	5	0.72
Illness coherence	The symptoms are puzzling to me (r), it does not make any sense to me (r)	5	0.70
Emotional representations	When I think about it I get upset, I get depressed when I think about it	6	0.85
Causal attributions (IPQ-R)			
Heredity	Hereditary—it runs in the family	1	—
Chance	Chance or bad luck, ageing	2	0.35 [~]
Risk factors	Diet or eating habits, smoking, alcohol, pollution, own behavior	5	0.82
Psychological functioning	Stress, emotional state, mental attitude, family problems or worries, personality, overwork	6	0.89
Immune system	Germ or virus, altered immunity, accident or injury	3	0.59 [~]
Coping (UCL-29)			
Social support seeking	Sharing worries, showing feelings, looking for understanding	5	0.84
Distraction seeking	Seeking distraction, meeting happy company, thinking about other things	4	0.77
Active coping	Observe the problem, think of different options, make directed action plans	4	0.79
Passive coping	Pessimistic view, feeling overwhelmed, feeling incapable of dealing with it	3	0.70
Religious coping	Praying, seeking comfort in religion, thinking it has a meaning	3	0.82
Adapting expectations	Changing expectations, demands, needs, priorities	3	0.75
Comforting thoughts	Thinking worse things can happen, saying it will	3	0.56 [~]

The Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views:

How much does your illness affect your life? 0 no affect at all 1 2 3 4 5 6 7 8 9 10 severely affects my life										
How long do you think your illness will continue? 0 a very short time 1 2 3 4 5 6 7 8 9 10 forever										
How much control do you feel you have over your illness? 0 absolutely no control 1 2 3 4 5 6 7 8 9 10 extreme amount of control										
How much do you think your treatment can help your illness? 0 not at all 1 2 3 4 5 6 7 8 9 10 extremely helpful										
How much do you experience symptoms from your illness? 0 no symptoms at all 1 2 3 4 5 6 7 8 9 10 many severe symptoms										

How concerned are you about your illness? 0 not at all concerned 1 2 3 4 5 6 7 8 9 10 extremely concerned										
How well do you feel you understand your illness? 0 don't understand at all 1 2 3 4 5 6 7 8 9 10 understand very clearly										
How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?) 0 not at all affected emotionally 1 2 3 4 5 6 7 8 9 10 extremely affected emotionally										
Please list in rank-order the three most important factors that you believe caused <u>your illness</u>. The most important causes for me:- 1. _____ 2. _____ 3. _____										

SRM applied to lung cancer

Illness representation:

Following a diagnosis, the individual will analyse, internalise and interpret the meaning of their illness

Individual becomes an active problem solver

Faced with two phenomena: the perceived reality of the illness and their emotional reaction

Internal and external stimuli (previous experience with the illness, social and societal influences) determine the illness representation

E.g. a newly diagnosed lung cancer patient who is currently smoking, may interpret their increased cough and worsening shortness of breath as symptoms of lung cancer

Depending on past experiences with these symptoms and influences from health care providers/media/family/friends, an illness representation is formed by the patient in respect to their continuation to smoke after diagnosis

SRM and lung cancer cont.

- Aside from recognising the signs and symptoms (*identity*) of the disease, other components of this illness representation are cause, consequence, control and timeline (the 5 key dimensions)
- The patients perception of lung cancer will influence the interpretation of the *cause* of the disease, linking past or continued smoking with the cause of the disease
- The *consequences* of continuing or stopping smoking will be internalised and made part of their illness representations
- The *perceived control* of lung cancer symptoms and disease and whether quitting or continuing smoking will have an affect upon the symptoms and stage of the lung cancer, become part of the illness representation
- he smoker's ability to change the overall *timeline* or prognosis of the diagnosis, with respect to quitting or continuing smoking, will be an important component of the illness representation.

Illness representations cont.



They are complex and dynamic



The internal and external stimuli changes the illness representation of time and guides the response to the health threat



Internal stimuli such as *side effects of treatment, public opinion on the causes and the prognosis*, will shape the illness representation of the course of the disease

Emotional representations

Emotions are also integral to illness representation and develop simultaneously with the cognitive component.

Fear, anger, depression or anxiety can motivate the individual to develop an action plan (coping procedure)

Can also be so overwhelming, resulting in less or no action taken (with respect to the disease)

After a patient has had the opportunity to consider the diagnosis, prognosis, and proposed medical treatment, the patient's illness representation may change.

These representations directly influence the coping procedure

Coping procedure

- The illness representation drives the individual's coping strategies.
- The individual develops a response plan or procedure to cope with the illness representation
- The selection of a coping procedure is guided by the illness representation concept
- A smoker may choose to cope with the new diagnosis of lung cancer by either quitting or continuing to smoke.
- The consequences of quitting smoking may involve physical and psychological factors (both positive and negative) such as decreased shortness of breath, increased nicotine withdrawal symptoms , increased family support, and improved survival
- The consequences of continued smoking may result in worsening pulmonary symptoms and possible decreased long-term survival
- The patient may continue to smoke to avoid the additional stress of quitting smoking during this already stressful time.

Outcome appraisal

An individual will engage in on going *outcome appraisal*

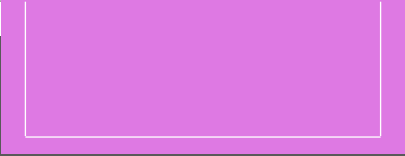
Or, the analysis of the consequence of their coping procedure

The outcome appraisal is the repeated evaluation of the coping procedure (e.g. continued or quitting smoking)

May be influenced by quality of life, clinical response to treatments, symptoms

Each influences the evaluation process

Constant feedback loop, fluid and dynamic model



RESEARCH INTO ILLNESS PERCEPTIONS

Cancer

Haematological cancer survivors with illness perceptions that represent more negative consequences, attribute more symptoms to their illness (identity); and have a poorer illness understanding (coherence) were more often substantially fatigued

Those who experience more consequences of their disease, attribute more symptoms to their illness, and have a poorer illness understanding, have a higher risk to experience substantial levels of fatigue even years after diagnosis (Schoormans et al., 2020)

People with higher perceived control are more likely to engage in supportive interventions (Stephenson et al., 2021)

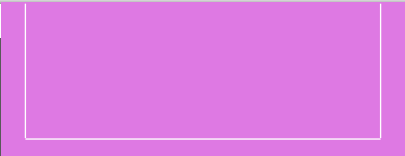
Diabetes

Cognitive and emotional representations of diabetes and diabetes knowledge are key determinants of patients self-care practices

- Important for targeting interventions to encourage adherence to self-care practices (Kugbey et al., 2017)



Sense of personal control is associated with good glycaemic control, then diet and medication adherence (Hashmi et al., 2022)



SUMMARY

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