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Fostering resilience and care for the family in the context of a life limiting cancer

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What is resilience?

‘Resilience refers to a *dynamic process encompassing positive adaptation within the context of significant adversity*.

Implicit within this notion are two critical conditions:

(1) exposure to significant threat or severe adversity; and

(2) the achievement of positive adaptation despite major assaults on the developmental process’

“bouncing back”

Luthar, Ciccheti & Becker, 2000

‘resilience is considered a dynamic mechanism that changes over time and can be affected by life circumstances, one’s environment and situational as well as contextual factors’

Seiler & Jenewein (2019)

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Resilience in cancer

Associated with

- Lower levels of distress
- Better quality of life
- Improved ability to self manage

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What are the threats and adversities faced by individuals with a pancreatic cancer diagnosis?

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Things that may be visible…

Physical effects of surgery, chemotherapy, radiotherapy

- pain, nausea, poor sleep etc
- multiple health care appointments
- physical effects of the disease

Disruption to normal routines and plans

- employment / career / study
- within the family: carer / parent / grandparent
- relationship with friends / family
- travel / hobbies / sports / activities

Significant losses and changes that need to accommodated e.g., financial stress

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Things that may not be visible…

GRIEF and LOSS
Uncertainty
Loss of control
Reactivation of prior trauma
Lost autonomy / dependency
Future

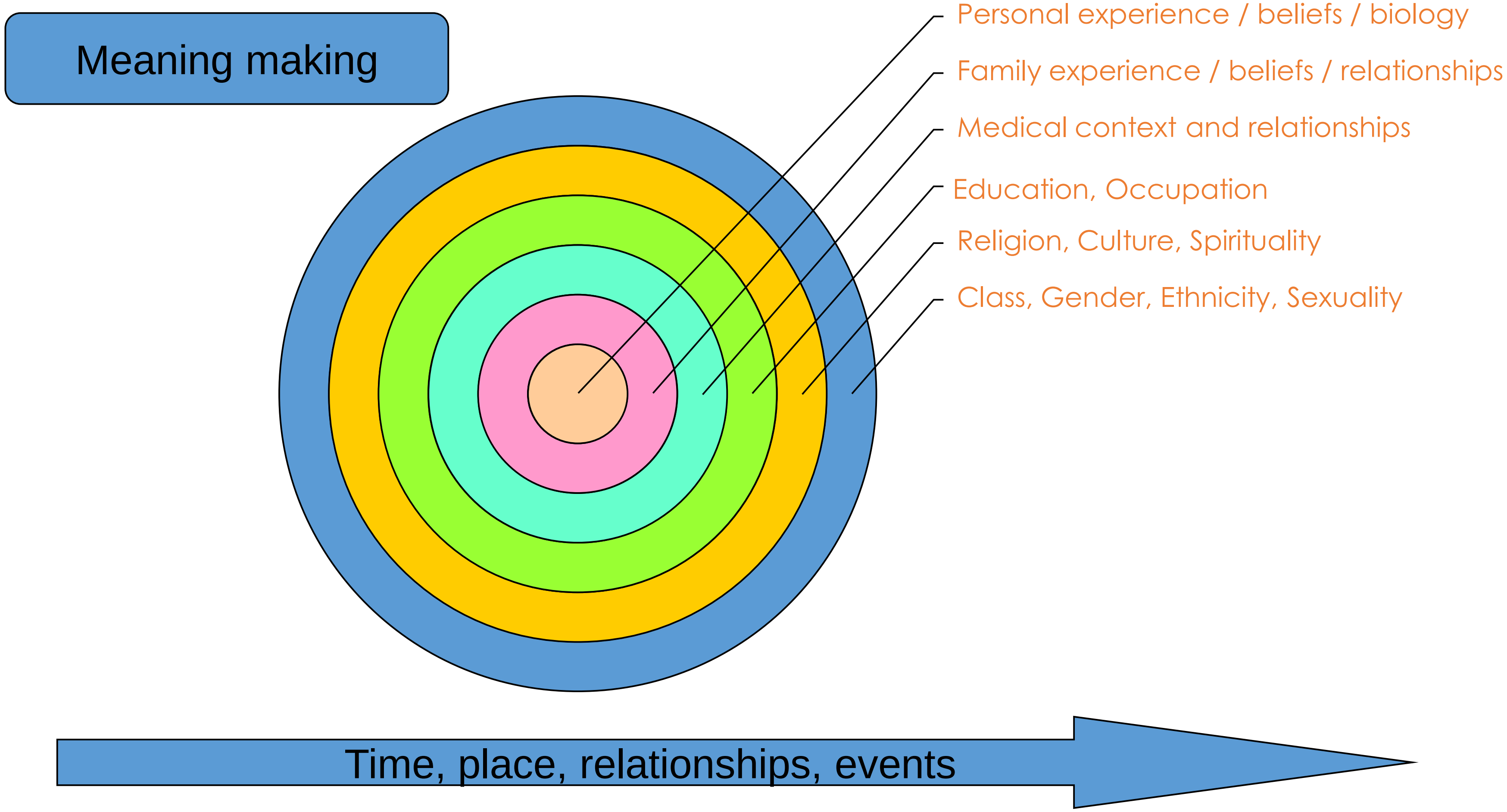
EMOTIONS
Anxiety
Anger
Sadness
Guilt
Stress
Regret

BELIEFS
The world is fair
The world is safe
I can be helped
Cause of cancer

EXISTENTIAL
Fear of death and dying
Meaning, purpose, legacy
Spirituality, afterlife

RELATIONSHIPS
Who am I to other people?
Who am I with cancer?
Who am I to the medical team?
How do I relate to my body?

Context, Social Systems and the influence of time, place, relationships, events



Meaning making

Personal experience / beliefs / biology

Family experience / beliefs / relationships

Medical context and relationships

Education, Occupation

Religion, Culture, Spirituality

Class, Gender, Ethnicity, Sexuality

Time, place, relationships, events

What factors determine resilience?

What does the research say?

Early life experience & prior traumas

Personality related variables

- self-esteem / self concept, hardiness, sense of coherence

Coping strategies

- problem focussed vs. non-adaptive (e.g., drinking)

Cognitive flexibility vs. interpretation biases

- improved ability to take different perspectives on situation

Optimism, Hope

Spirituality

Social context

- support provided by family and friends; different types of support
- sense that one is loved, esteemed and valued

Not predicted by

- Disease severity, time since diagnosis

Seiler & Jenewein (2019); Gordon, Fawson et al (2021)

What can we do to foster resilience?

How do we support resilience?

Be **patient centred** – what is important for patient?

→ Changes according to circumstances, patient's disease progression, emotions etc

Values: How we want to engage with the world, with the people around us and with ourselves

- Meaning, connecting with a sense of purpose
- Valued activities / maintaining routines
- Spirituality

Social Support: Help patients to connect with **supports** around them

→ Can some roles be maintained?

How do we support resilience?
Facilitating Coping

Look out for current and previous examples of coping

‘Has there been any other time in life where you’ve felt low?’

‘What helped you cope last time you had chemotherapy?’

Reinforce **self-belief** and a **sense of control**

Perception of **coping ability + resources**
vs. **perceived demands and threats** posed by cancer

(Lazarus & Folkman, 1984; Seiler & Jenewein, 2019)

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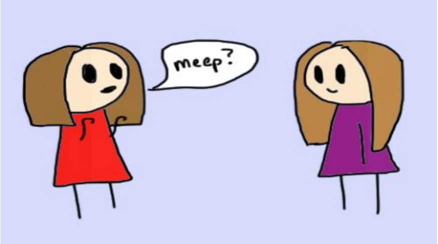
How do we support resilience?



Listening, ‘Being with’

→ Allowing for expression of feelings

Empathy and self compassion

Cognitive flexibility

Complexity of positive thinking: ‘Be Strong’, ‘Keep positive’

Help patients to *be with* difficult emotions

It’s ok not to feel ok all of the time

What about family and friends?

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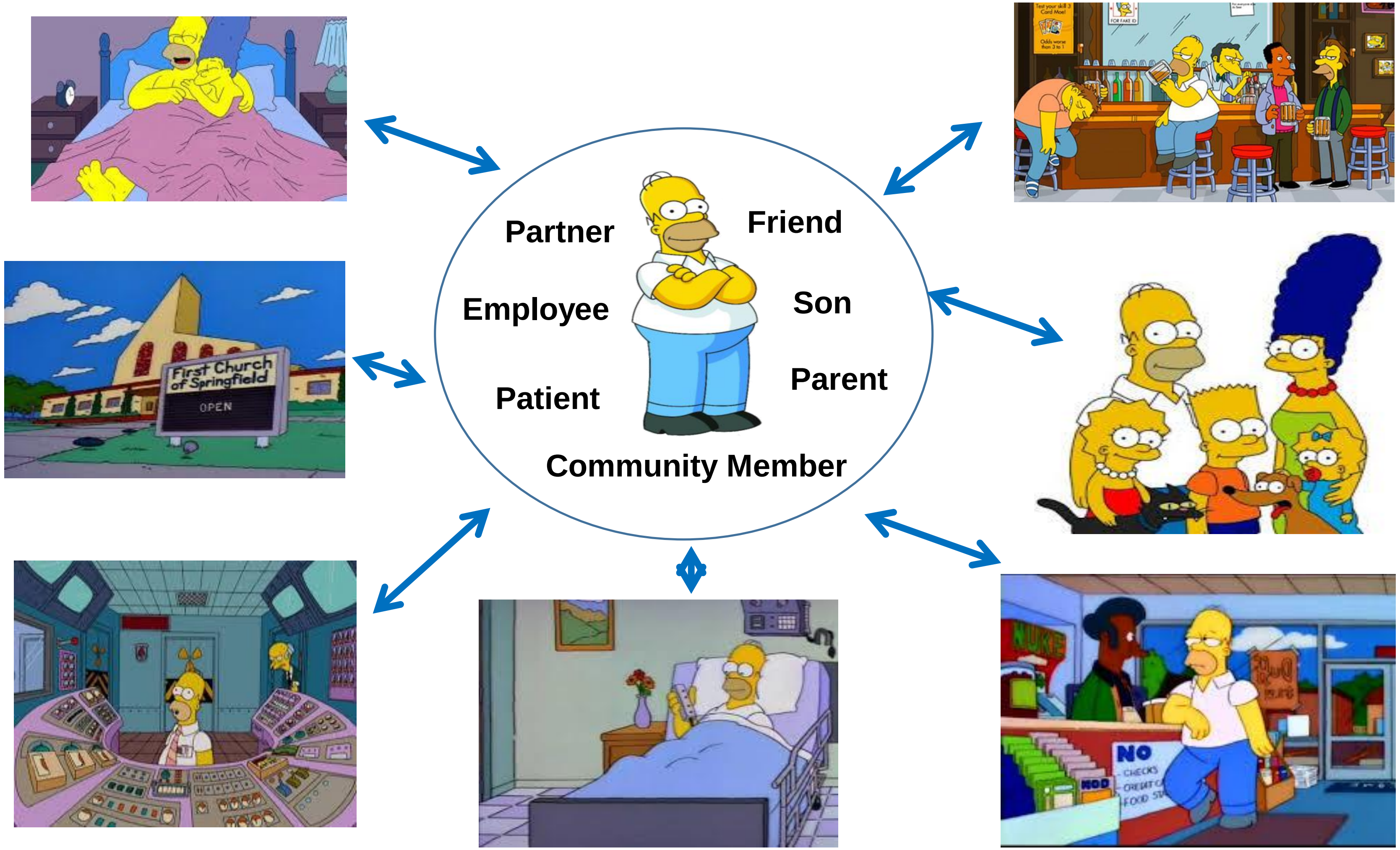
Roles and relationships



Partner

Friend

Employee

Son

Patient

Parent

Community Member

Level 2 Psychological Skills Training, Janssen, Reeder & Alexander, 2018

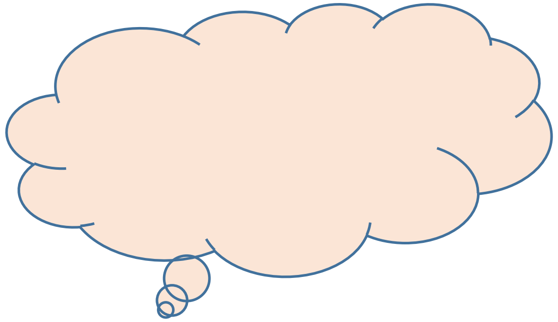
Impact of cancer on relationships

Fears and life adjustments affecting patients also affect partners and families

Hard for loved ones to know how to support

Fears around life without the patient

Past losses



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Talking with loved ones

How do we help patients to have ‘tender conversations’ with family members?

- what matters to the individual?
- who might patients want to speak with?
- various relationships
  - partners, children, parents, work colleagues, friends
  - Exes? Work colleagues? Friends? Acquaintances?

(Kubler-Ross, 1969; Mannix 2018)

Impact of cancer on children

How will this affect my children?

Will they be able to understand / cope?

Who is going to

- take them to nursery, school?
- take them to ballet, soccer, gymnastics, the park, art club, the movies etc ?
- support with homework / make sure they revise for A-levels
- think about college / university / apprenticeship choices
- **look after them? care for them? love them?**

“I want things to be normal”

How will they grow up if I’m not here?

Affected by

age, attachment security, personality, development / disability, past experience of death etc

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Talking with children

Should I tell them?

When should children be told?

Where?

Who should tell them?

What to tell them?

“what if I get upset?”

Marie Curie, 2019

Talking with children

Questions and concerns

is it my fault?

will Mum/Dad die? when will it happen? what about the other parent?

why can't the Drs make it better? why do people die? will it hurt?

can I catch it?

Emotions

fear, worry, threat, upset, sadness, confusion, shock, guilt, anger, loneliness

see-saw in and out of an emotion

Behaviours

distress could manifest as tearfulness, separation anxiety (being 'clingy')

difficulty concentrating, 'acting out' → "they don't seem to care"

at times, children can appear very accepting or ambivalent, later, they may become very distressed

→ can be confusing for adults

Marie Curie (2019); MacMillan Cancer Support (2019); Level 2 Psychological Skills Training, Janssen, Reeder & Alexander (2018)

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Principles of communicating with children about cancer

a) Honest and Open

b) Check for understanding

c) Ask how they are and encourage child to express feelings and ask questions at child's pace

d) Talk with school?

e) Maintain routines

f) Prepare the child for what to expect

g) Identify resources and supports

- RipRap; Winston's Wish; Child Bereavement UK; Fruitfly Collective

→ Reassure children that they are loved, valued and safe

MacMillan Cancer Support (2019); Level 2 Psychological Skills Training, Janssen, Reeder & Alexander (2018)

Thinking about end of life

Incredible enormity of the task

→ parents usually still processing this information themselves

Creating memories

- Spending time together
- Creating a memory box; collecting photos and souvenirs
- Arts and crafts together; reading together

Hospital visits

(Marie Curie, 2019)

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Final thoughts…

Capacity for resilience varies significantly

→ biological, personal, social, contextual

Avoiding an individualising or ‘self help’ message

→ some patients will require more support

→ some patients will find things that others find to be helpful as unhelpful

Work with the person and their context

Hold family and friends in mind

Any questions or reflections??

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