Making sense of Resilience in Palliative Care

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Pain at the end of life. The response is not only medication

“The world is full of suffering but also of the overcoming of it”
Helen Keller, 1903
Unlocking Resilience in Hospice and Palliative Care

Patients
Families
Communities

Resilience =
“Ability to have faith in the future”
Course Participant
Contradictions, paradoxes and ambiguities of palliative care

Great moments of Sorrow ................................................................. Great moments of Joy

Adversity .................................................................................. Achievement

Ghandi, Schweitzer, Mandela - spirit not depressed
by witnessing repression and suffering

Bereavement ............................................................................... Growth
Loss

"I have lost a friend but I have gained a companion for the rest of my days."
(Henri Nouwen (1998) when his beloved friend, Adam died. ('Sabbatical Journey')
Contradictions, paradoxes and ambiguities of palliative care

Acknowledge ................................................................. Deny
Hope ................................................................. Despair
Talk ................................................................. Silence
Receive ................................................................. Reject
Intimacy ................................................................. Distance
Make future plans ........................................................ Stay in past / present
Death ................................................................. Life
Falling apart ............................................................. Unity
Collapse ................................................................. Resilience
“The window to suffering can be a window to peace and opportunity”

Cicely Saunders  In Ferrell & Coyle, 2001
RESILIENCE & Palliative Care
Achievement through Adversity

“Resilience is the ability of a social system to grow and develop in the face of difficult circumstances.”

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New Series

2005
28 January
9 February
8 March

RESILIENCE IN PALLIATIVE CARE – WHAT IS IT?
RESILIENCE AND CHILDREN
RESILIENCE AND THE SEARCH FOR MEANING

St Christopher's Hospice

St Christopher's Hospice
Three essential components of palliative care

Symptom relief
Psychosocial support
Teamwork and partnership

Twycross (1995)
Introducing palliative care
“Pain is the resultant of a conflict between a stimulus and the whole individual”

Leriche, 1939
The surgery of pain
Sheffield model for supportive care

CANCER THERAPIES
Life-prolonging
Life-maintaining

SUPPORTIVE CARE
eg, palliative care, information services, pain clinic, physiotherapy, SW, chaplaincy, primary care

Ahmedzai, Walsh 2000
Making Sense of Resilience in Palliative and End of Life Care

1. Resilience - what is it?

2. Why is it relevant to palliative care?

3. What we can do to enhance resilience?
1. Resilience – what is it?

- Achievement *through* adversity
- Achievement *despite* adversity
- Achievement *thanks to* adversity

International Resilience Project which collected data from thirty countries: a ‘universal capacity which allows a person, group or community to prevent, minimise or overcome damaging effects of adversity’ (Newman and Blackburn, 2002).
What is ‘Resilience’?

Latin root of Resilio = to leap back
Resilere = to rebound

\[ U_r = \frac{\sigma^2}{2 \times E} = 0.5\sigma\varepsilon = 0.5\sigma \times \left(\frac{\sigma}{\varepsilon}\right) \]

Bluglass, 2007
Human resilience refers to a whole set of interacting processes.

Why do some people break down whilst others rise to the challenge?

Do we allow people who are struggling to grow into resilient beings?

Is resilience the same as empowerment?

How do we promote resilience?
Resilient communities

The London Bombings

- Resilient Londoners
- Resilient spirit
- Economic resilience
- Market resilience

The Queen:

“People are turning to resilience, humour and courage”

David Cameron “British resilience” Diamond Jubilee

4 June 2012
Resilience – what is it?

“The capacity of an individual person or a social system to grow or to develop in the face of very difficult circumstances.”

Vanistendael, 2002, Resilience et spiritualité, Geneva
“It is not the definition of resilience that is important, it is the philosophy that resilience can be enhanced”

Fazio & Fazio (2001)

Multiple pathways to building resilience rather than a single mechanism
What is ‘Resilience’?

- Think of one or more persons you consider ‘resilient’

- E.g. a patient; bereaved person; friend with traumatic background; someone in the news, a colleague in your team

- What are their characteristics?
Seligman, 1998
from depression to positive psychology

- Courage (not sense of fear)
- Optimism (having internal dialogue)
- Interpersonal skill
- Work ethic (sense of direction)
- Honesty (personal integrity)
- Perseverance
Resilient People – the Research

- Capacity to reframe adversities
- Strong social support networks
- Belief that one’s own efforts can make a difference
- One other supportive person
- Attractiveness
- Intelligence
- Participation in other outside events
- Not to be sheltered from challenging situations
- Humour

Capacity to discover sense; meaning; coherence
“Acts of war, destruction and disaster have occurred down the centuries. At times, those directly affected may struggle to see any sense in their lives.

Yet one of the amazing aspects of the human race is that out of disaster and catastrophe can come determination, compassion and inspiration”

Martin Newman, Editorial, Bereavement Care, 2005
Change welcomed – normal part of life

Sense of commitment

Internal locus of control; they take responsibility

The question is not so much “what is the meaning of life?” as “what makes me feel that my life has some meaning?”

Vanistendael, 2005
HIDDEN from the HOLOCAUST
Stories of Resilient Children Who Survived and Thrived

Kerry Bluglass
HAVE YOU SEEN MY LITTLE SISTER?

JANINA FISCHLER-MARTINHO
Fredrickson, 2001 and Tugade and Fredrickson, 2004

Resilient people are able to find positive meaning within stressors and have greater access to stored positive information that enables them to avoid being overwhelmed by the negative experiences and emotions that everyone goes through.
2. Why is resilience relevant to palliative and end of life care?

- Working with patients’/carers’ inner strengths and resources
- Promoting self-help
- Empowerment/autonomy
NEED, DEMAND AND RESOURCE – wider context

- Rising expectations of healthcare
- Conflicting rhetoric of choice and equity
- Ageing and multiple morbidities in pop
- Split and dispersed families
- Single person households
- Changes in demographics and disease
- BBC poll 2005 – little change in public attitudes
- Healthcare Commission 2007 – 54% complaints
- Constrained financial and professional resources

Thanks Barbara Monroe
I probably won't make it, but I'm going to enjoy every second I have left.

Grandstand's first female presenter **HELEN ROLLASON** is determined to face the challenge of illness with courage and humour and help others not to be afraid of cancer.

**Helen's Story**

**Tuesday BBC1, not Scotland**

She was warned she wouldn't live beyond last month, yet here we are, lunching in an Essex restaurant near her home, and she is chirpy, amusing and far from self-pitying as she tells a humbling story of courage and almost unrelenting optimism. There are no mock heroes, and she warns lest viewers think she is capitalising on her cancer by allowing herself and her 18-year-old daughter, Nikki, from whose father she is divorced, to be followed by cameras since June. "It's cringean-making to expose yourself, but I'd like to think it's an uplifting, rather than sad, film. I'm trying to help people not to be afraid of cancer, although I'm far from complacent. A friend of 35 was gone in three weeks. But I felt I could allay fears because not every sufferer dies. OK, I'm terminally ill and probably won't make it, but I'm doing everything I can." 

**THE ANDREW DUNCAN INTERVIEW**

so knackered it takes several attempts to get any blood out of me these days." Sometimes, in the depths of the night, she admits to feeling "sad". Yesterday was one of the few bad days when she was so ill she curled up on her sofa and wept. "I thought, 'Oh, God, I've had enough.' Images come into your mind of beyond your death and you wish they didn't. I imagine how life will be for Nikki, someone sorting through my clothes, the funeral. You have to give yourself a hell of a strict talking to and say, 'It's not going to happen, so stuff it.' Certain music always does me in like Perfect Day [the Lou Reed song used last year by the BBC as a promotional tune because when I first heard it I thought I'd never have another perfect day. But since then I've had lots of blissful ones, which I appreciate. I'd like to do more work, and I should have been at the Commonwealth Games [in Kuala Lumpur last month] but the guys phoned me all the time..."
How would you define resilience?

The capability of individuals and systems to cope successfully in the face of significant adversity or risk. This capability develops and changes over time, and is enhanced by protective factors within the individual/system and the environment, and contributes to the maintenance or enhancement of health.

Source: Reid, Stewart, Mangham, & McGrath (1999). Atlantic Health Promotion Research Centre.
Resilience

Protective factors

Vulnerability factors

Risk
Unlocking Resilience – Restoring Balance

- Growth
- Coping/adapting
- Strengths
- Capacity for change
- Empowerment
- Resources
- Being strong
- Getting act together
- Opportunity

- Vulnerability
- Risk
- Concern
- Dysfunction
- Overwhelmed
- Deprived
- Helplessness
- Breaking down

Crisis
Resilience in psychosocial, spiritual and family care

**SPIRITUAL**
- Meaning
- Connection
- Hope
- Forgiveness
- Reconciliation

**PSYCHOLOGICAL**
- Self-esteem
- Respect
- Control
- Autonomy
- Decision-making

Compassion and dignity
“A safe place to suffer”
Family/Relationship Care
“Cancer can affect the family in much the same way as it affects a body, causing deterioration if left untreated”

Colin Murray Parkes, 1975
Key determinants of family functioning

- **Cohesiveness**
  Family’s ability to function as a team

- **Conflict**
  Family’s ability to resolve conflict

- **Communication** (expressiveness)
  Communication of thought and feeling

Bloch and Kissane, 2002
3. What can we do to promote resilience?

Resilience Formula =

Growth = challenge + support

“Not rocket science”
Promoting Resilience in Palliative Care

A strengths-based approach

- Skills, competence, talents
- Harnessing individual qualities
- What makes the family pull together?
- Uncovering family strengths
- Identifying supportive individuals
- Unlocking community resources
- Identifying and prioritising goals
- Discovering fulfilling activities
- Finding the why and how
- Finding a narrative and meaning
- What remains and attracts you?
- Something to aim at & achieve

Oliviere and Monroe, 2008
COPING AND RESILIENCE

- Self-esteem
- Exercise control
- Realistic hope
- Use of ‘healthy’ defence mechanisms including humour, denial and distraction
- Capacity to recognise achievements and positive meaning in the present
- Good memories – telling your story
- Supportive relationships
- Appropriate information and good communication
Tools in Resilience Work

- Empowered communities
- Robust management/organisation
- Accurate information
- Stories and narratives
- Brief Interventions/short-term focused
- Creative activities
- Public education
- User involvement initiatives
- Self-help groups
- Family systems approach
10 ways to build Resilience

1. Make connections
2. Avoid seeing crises as insurmountable problems
3. Accept that change is part of living
4. Move towards your goals
5. Take decisive actions
6. Look for opportunities for self-discovery
7. Nurture a positive view of yourself
8. Keep things in perspective
9. Maintain a hopeful outlook
10. Take care of yourself

Source: American Psychological Association, 2007
Patients need:

- Communication
- Compassion
- Collaboration
- Care