

Chronic Illness, Death & Dying

Session outline

- Lecture:
 - Psychosocial impact of chronic illness
 - Meaning making and benefit finding
 - Terminal illness and palliative care
 - Narratives in medicine: an example of patient stories
- Seminar:
 - Living with secondary breast cancer: peer review of focus group study paper

Chronic illness

- The proportion of people living longer and with chronic illnesses has increased due to improvements in treatments that reduce disease and delay death
- Living with chronic illness can have a significant impact on quality of life and wellbeing:
 - Adjusting to symptoms and potential disability
 - Challenges of self-management
 - Emotional impact on self esteem and self image
 - Impact on relationships
 - Living with an uncertain future
- Examples of chronic illness include:
 - Epilepsy
 - Chronic fatigue syndrome
 - Diabetes
 - Cancer
 - Arthritis

Psychosocial impact of chronic illness

- From what we have learned already in this module it should be clear that:
 - There will be large individual differences in perceptions of QoL amongst individuals with chronic illness
 - Beliefs about the illness and their own coping resources will effect how people cope emotionally and practically with living with chronic illness
 - Psychological models provide important framework for understanding the impact of chronic illness
 - Role for psychological interventions to help people manage and live with chronic illness.

Psychosocial impact of chronic illness

Common emotional responses to illness include:

- Anxiety
- Anger
- Denial
- Depression

– Chronic illness can also lead to a sense of learned helplessness (Seligman, 1975).

Crisis theory (Moos and Schaefer, 1984)

- Humans seek social and psychological equilibrium which is disrupted with the diagnosis of a chronic illness
- Coping efforts attempt to re-find equilibrium

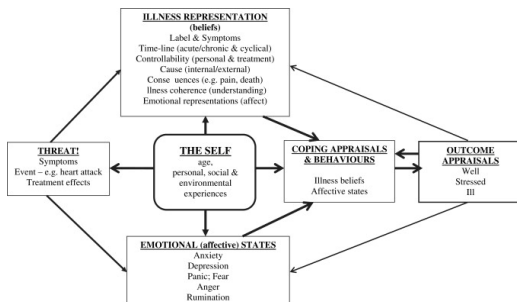


Critical thinking.....

- Apply your understanding of the psychological models we have discussed so far in this module to explaining how people may respond to the diagnosis of a chronic illness....

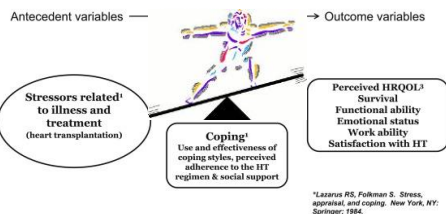


Self regulation model



Coping with chronic illness

- Transactional model of stress and coping (Lazarus & Folkman, Stress and Coping Framework)



¹=variables examined in this report

²HT=heart transplantation

³HRQOL=health-related quality of life

*Lazarus RS, Folkman S. Stress, appraisal, and coping. New York, NY: Springer, 1984.

The role of positive emotions in coping

- positive emotions can play an adaptational role in helping people cope with chronic illness and associated with better health outcomes
 - positive reappraisal
 - problem-focused coping
 - Benefit finding
 - Post-traumatic growth

(Antoni et al., 1991; Folkman, 1997; Fredrickson & Levenson, 1998; Folkman & Moskowitz, 2000).

Psychological interventions in chronic illness

Focus of psychological interventions for chronic illness tend to be around:

- Enhancing quality of life
- Improving appropriate self management of illness
- Increasing psychological wellbeing
- Improving appropriate use of health care provision
- Reducing pain and symptoms

Psychological interventions in chronic illness

Psychological interventions for chronic illness can include:

- Cognitive behaviour therapy
- Psychodynamic therapy
- Counselling
- Motivational interviewing
- Stress management interventions
- Support groups
- Expressive writing
- Relaxation training

Critical thinking.....

- Apply your understanding of the psychological models we have discussed so far in this module to identify some appropriate interventions to help people live with chronic illness



Critical thinking.....

- What factors would you need to consider in order to be able to show that your intervention has been effective?



Terminal Illness:
"the ultimate existential crisis"



Illness Narratives and Patient Voices..... an example



Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

“I almost feel like a bit of a second class citizen”: A
focus group study of the experiences of women
diagnosed with secondary breast cancer and their
support needs

Margaret Ann Baker, ABMU
Dr Ceri Phelps, Registered Health Psychologist, University of
Wales Trinity Saint David

Background

- ☐ Women with a diagnosis of secondary breast cancer have complex and often unmet needs
- ☐ higher level of psychological distress compared to that at receiving a primary diagnosis (Breast Cancer Care, 2009; Reed et al. 2010; Mahon et al. 1990; Parle et al., 2001)
- ☐ high levels of psychosocial morbidity (Cohen, 2002; Coristine et al 2003).
- ☐ Feelings of uncertainty, lack of control, stigma, abandonment, anger and isolation (Hanson-Frost et al. 2000; Krigal et al, 2014; Pollin; 1995; Mosher et al., 2013).

Study context

- ☐ MA Counselling Practice Dissertation Project, UWTSO
 - ☐ submitted 2014 (data collection continued)
- ☐ Student researcher a breast cancer nurse
- ☐ Study continued beyond initial MA



Study aims and objectives

- To explore women's experiences surrounding their secondary breast cancer diagnosis.
- To gain an understanding of the emotional support and information needs of breast cancer patients since their secondary diagnosis.
- To discover whether women with secondary breast cancer feel their needs have been met.

Methods

- ☐ Qualitative focus group methodology
 - ☐ ideal way of obtaining rich narrative information about shared experiences of health and illness (Wilkinson, 1988; McLeod, 2011)
 - ☐ previously used as an aid to exploring and planning future needs of women with a diagnosis of secondary breast cancer (Breast Cancer Care 2008) and other cancer patient groups (e.g., Hughes & Phelps, 2010).

Methods

- ☐ Purposive sample of secondary breast cancer patients across ABMU
- ☐ 12 women participated in one of two focus groups (6 per group).
- ☐ Secondaries in bone, brain, liver and lung.
- ☐ Ages ranged between 29 & 70 years.
- ☐ Ethical approval obtained from South West Wales Research Ethics Committee.

Data Collection

- ☐ Each focus group was held at Maggies Centre within the hospital grounds
- ☐ Focus groups lasted approx. 90 mins
- ☐ The main researcher (AB) facilitated the group with the use of a semi-structured topic guide with the help of a co-moderator (CP).
- ☐ Data was digitally recorded, transcribed and anonymised

Findings: Thematic Analysis

Table of superordinate and sub-ordinate themes		
Superordinate theme 1: A loss of support	Superordinate theme 2: A changing identity	Superordinate theme 3: Living with no cure
Sense of abandonment	Self stigma	An uncertain future
Needing time to reflect	Walking in their shoes	Resilience
Perceived reluctance to explore the death question	A common identity through shared experience	Reluctance to seek psychosocial support
A missing link		

Superordinate theme 1: A loss of support

Sense of abandonment

"I feel the same. Once you find out they leave you. You don't know nothing about it. You gets told and then you just walk out of there and you think well where do I go from here?" (G1)

"I was only finding out that I had secondaries this year and I feel totally abandoned by you know any support what so ever since I got referred to Oncology"(G1).

Superordinate theme 1: A loss of support

Needing time to reflect

"I felt, I don't know perhaps, if I reflect a bit, perhaps I just blanked out and I didn't take it in, I just switched off. It was the most unbelievable day, I just felt I was left to walk out and find my own way. What shall I do?"

Superordinate theme 1: A loss of support

Needing time to reflect

"I mean I don't think any of us will ever forget the day you told that initial conversation and you walk out of the room and you're in there and you think right keep your head straight ask the questions, and I'll ask the questions and then you go outside and you sit down and you just shocked, and of course that shock wave may come over you within a couple of hours, oh I want to ask this, I want to ask that."(G1)

Superordinate theme 1: A loss of support

Perceived reluctance to explore the death question

"when they've said you've got cancer again and I just went and I said 'am I going to die?' and I don't know why I said it? but they said 'well I don't know' ! and I will never forget, never ever and I don't' want to see them" (G1.)

Superordinate theme 1: A loss of support

Perceived reluctance to explore the death question

*"He says you do realise you can't be cured, you do realise you can't be cured"
"I find that really annoying when I go to my Oncologist, and say, well I would say in what a 20 minutes consultation that if I don't hear that word 3 times (G1)*

Superordinate theme 1: A loss of support

A missing link

"it would be nice if somebody could be in that middle to help him and help us because then you think, because I said I can't phone up I said, because they think I'm being a nuisance"(Edna)

Superordinate theme 2: A changing identity

Self stigma

"I mean my primary care it was fantastic - was amazing - and the care I got was amazing but I just think 13 years, you get secondary breast cancer and I almost feel like a bit of a second class citizen really, you know, how are you meant to feel?"

Superordinate theme 2: A changing identity

If they have got primary cancer, not secondary cancer it's quite possible they will get better so they don't need to see me crying and going oh yeah but sorry I'm not going to get better particularly if it's breast cancer, as so many people do get better"(G1)

Self stigma

Superordinate theme 2: A changing identity

"this is a group that is long overdue and I am really keen to support."

...I feel totally abandoned and unsupported, and yeah so I think something like this group is fantastic for me. Yeah."

A common identity through a shared experience

Superordinate theme 2: A changing identity

A common identity

first time I came to the group, it was a big comfort in that.....because it struck me that everybody looked normal and you think that you are going to be walking around you know with Doctor death over you . But everyone looked normal so that was a comfort and I was thinking well there is hope then. There is hope , where I had felt written off, and then I went home and I had pizza and wine cos I had been frightened to drink , frightened to have rubbish long sigh, it gave me hope. The group the first time gave me hope , that I didn't have before , it lifted me .

Superordinate theme 3: Living with no cure

An uncertain future

"you're sitting there and you get all these dark thoughts, and you start thinking Oh God, in my case, it was what if I'm not there to see my kids finish school, or what if I'm not there to see them when they need me."

Superordinate theme 3: Living with no cure

Resilience

"cos I challenge it cos I'm like yourself, it's not cured until the day I die, until that point"(Susan)

"Well I won't let it identify me. I'm far more, I've got far more to say about myself, even though I feel as if I've got myself into a bit of a mess"(Andrea, G1)

"everyone tells me I'm not curable, I'm only not curable when I get to that point when they say actually there's nothing else we can do for you"(Hannah).

Superordinate theme 3: Living with no cure



Conclusions: bridging the gap

- ☐ Need to bridge the existing gap which appears to exist between many secondary breast cancer patients' needs and the type of support they receive from their oncology teams.
- ☐ Women with secondary breast cancer have unanswered questions, fears and frustrations
- ☐ Feel stigmatised, isolated and that their voice is often unheard
- ☐ Need to also better understand the clinicians' attitudes, beliefs and behaviours

Conclusions: bridging the gap

- ☐ Need to identify whether this gap can be/has been met by utilizing existing resource of breast specialist nurses into developing the role of a secondary breast cancer nurse.
- ☐ The importance of informal peer support networks also clearly a valuable support mechanism to help women with secondary breast cancer feel less stigmatised and isolated.

Wider implications

- ☐ Importance of capturing the “patient voice” in understanding perceptions of “good care” and in shaping the future delivery of health care services (Begley et al., 2014).
- ☐ Greater patient engagement can also assist in decision making and policy planning

Acknowledgements:

- Ann Baker
- The ladies who shared their stories so willingly
- ABMU for supporting the professional development
- Maggie's Cancer Caring Centre

