

5th International Congress of Breast Disease Centers 2015

“MULTIDISCIPLINARITY IN THE BREAST CENTER”

ANTWERP, ANVERS - February 5 - 7, 2015

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Quality of Life-The patients View

Breast Cancer

- Not just a terminal illness
- Survivors increasingly have a life expectancy of more than 5 years
- A chronic illness
- Health and psychological treatments (e.g. pain management, QOL)
- Similar to other chronic illnesses e.g. diabetes, asthma

Definition of Quality of Life

‘A personal sense of well-being encompassing a multidimensional perspective that generally includes physical, psychological, social, and spiritual dimensions or domains’

(Ferrell et al 1995)

AND

‘The overall enjoyment of life’

(National Cancer Institute 2015)

Quality of Life – 4 Domains

- Physical well-being is the control or relief of symptoms and the maintenance of function and independence.
- Psychological well-being is the attempt to maintain a sense of control in the face of life-threatening illness characterized by emotional distress, altered life priorities, and fear of the unknown, as well as positive life changes.
- Social well-being is the effort to deal with the impact of cancer on individuals, their roles, and relationships.
- Spiritual well-being is the ability to maintain hope and derive meaning from the cancer experience, which is characterized by uncertainty. (Ferrell 1997)

Evidence on Quality of Life

- Breast Conservation surgery-Higher body image and sexual functioning
- Systemic treatments-poorer QOL
- Adjuvant therapy-poorer QOL
- Depression and anxiety found years after the diagnosis.
- Symptoms eg pain, arm immobility, fatigue.
- Younger patients poor sexual functioning
(Montazeri 2008)

Quality of Life Issues

- Menopausal symptoms-endocrine effects
- Sexual functioning
- Infertility
- Body image
- Financial Problems
- Loss of independence
- Chemotherapy side effects
- Anxiety and Depression
- Fatigue

(Knobf 2006 Grimson et al 2007 Baucom et al 2006 Reich et al 2008)

Cancer Fatigue

Definition

‘An overwhelming sense of exhaustion and decreased capacity for physical and mental work regardless of adequate sleep’

(Mosby’s Medical Dictionary)



Cancer Related Fatigue

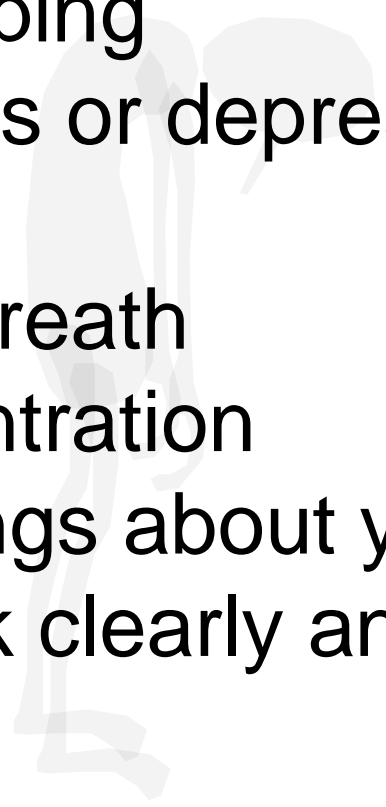
A phenomenon that is characterised by increased feelings of discomfort and decreased functional status that is related to decreased energy

(Holley 2000)

Fatigue has been identified as the most prevalent and disturbing symptom of cancer and its treatments

(Winningham et al 2001)

Symptoms of Fatigue

- Problems sleeping
 - Feeling anxious or depressed
 - Muscular pain
 - Shortness of breath
 - Loss of concentration
 - Negative feelings about yourself
 - Unable to think clearly and make decisions
 - Lethargy
- 

Predictors of Quality of life

- Poor Doctor Patient communication (Stewart 1995, Engel et al 2003)
- Additional co morbidity (Repetto et al 2003)
- Younger patients report more depression(Mor et al Northouse et al 1994)
- Arm Mobility (Erikson et al , Kwan et al 2002)
- Mastectomy v Wide Local Excision (Engel 2004, Ganz 2004)
- Anxiety depression low self esteem in Mx patients(Al-Ghazal et al 2000)

(Engel et al 2003)

Quality of Life Surveys

- Wales Cancer patient survey (2014)
- National Cancer patient experience (2014)
- Improving outcomes in Breast Cancer (Nice 2008)
- Quality of life of Cancer Survivors in England (2012) –Fear of Dying and Recurrence

Quality of life of Cancer Survivors in England (DOH2012)

- EQ 5D used as assessment tool
- 5.000 patients- 3,300 responses
- Median age 69 yrs
- 8% – 22% reported moderate or severe problems on the EQ5D
- Overall QOL related to co morbidities,disease status age and physical activity
- FACT Questionnaire tumour specific used

National Cancer Patient Experience (2014)

- Being told about side effects of treatment that might affect the patient in the future (56%)
- Being given information on financial help and benefits they might be entitled to (54%)
- Having a discussion with staff about taking part in cancer research, and then going onto take part (63%)
- Families or someone close to them having the opportunity to talk to a doctor if they wanted to (67%)
- There being enough nurses on duty to care for them in hospital (62%)
- Being asked which name they preferred to be called by (60%)
- Giving families or someone close to them all the information they needed to look after them at home (60%)
- Being given enough care and help from health and social services post discharge (59%)
- GPs and nurses at their general practice doing everything they could to support them whilst they were being treated (66%)
- Different professionals working well together to give the patient the best possible care (63%)
- Being offered a written assessment and care plan (22%)

Assessment Tools for Quality of Life

- EORTC QLQ-C30-Psychological function
- EORTC QLQ-BR23-QOL specific BC
- FACIT-G-QOL General
- FACT-B-QOL Specific
- FACT –B plus ES-Hormonal therapy
- BIBCQ-Body image after Breast Cancer
- FSAQ- Sexual Activity Questionnaire

Patient Stories-Support

‘The questions about my treatment, my doctor (GP) wouldn’t have been able to answer those and my consultant doesn’t give you enough time to ask those questions, so I wouldn’t have had anyone to go and talk to had it not been for my nurse’

(Breast Cancer Care)

Communication

‘The only advice we get, or the chance to ask questions, is when something is wrong, and then when we do ask we’re not always given the explanation of what to expect or how it’s going to affect us.

There are times you want to know something and there is no-one there to ask – we can cope at the hospital, but when we come away we’ve got nothing.’

(Breast Cancer Care)

Patient Stories-Fear

‘If I could Understand what was happening to my body then
I could understand the symptoms, then they wouldn’t be so
frightening’

(Van der Molan 2004)

Body Image

‘I haven’t been working and I’m wondering how I’m going to react when I have to wear a wig. Of course, there’s nothing to be ashamed about that, but still it’s such a huge step that one wouldn’t want to take, even though everybody knows I’ve got this terrible disease, but still, I wouldn’t want to show them everything.’

(Luoma and Blomqvist 2004)

Physical Functioning

They bring me my meals in bed, and it's so hard, because I just can't handle my normal everyday life by myself. It feels awful. I've never had to depend on other people like this. It's so difficult to accept this.

It's so tough to know that I'm totally dependent on other people, you know, to need other people's help all the time.

(Luoma and Blomqvist 2004)

Fostering Hope

‘It’s comforting as long as something is being done, I feel that there’s hope as long as I’m being treated’

Normality

‘When someone asked me what I considered a good life and what expectations I had on life, I just replied that a pint in a pub. It might be a tiny little thing that brings me back to everyday life. Of course, the kids are terribly important and I can’t forget that, but also the feeling that might make me feel good is really important. Little things that I was able to do before and then to realize that I’m still able to do those things.’

Social Functioning

‘I’ve tried to be like other people and to be together with them. I don’t really want to stay alone, and feel sorry for myself. I have to be on the move. It makes it easier. If I stay alone and think about things, it doesn’t really get any better. It’s much better to be out there and live your life like everyone else, or at least try to live as everyone else.’

Coping Strategies

I don't really want to tell anybody that I'm like this. I don't want to talk about it to strangers, cause I feel that people would start to feel sorry for me or something like that... I don't want any of that. I don't think that I've changed that much as a person. I'm still the same person, even if I've got this disease. That's probably why I don't want to talk about it to anyone.

I try to avoid very deep thoughts and I try to live for the moment, and when things start to get tough, I start thinking about practical matters.

Strategies to Help Quality of Life

- Psycho education intervention-(Meneses et al 2007)
- Exercise-Courneys et al 2003,Turner 2004,Young-McCaughan and Sexton 2001)
- Communication skill training-Fallowfield and Cella 2008 Fallowfield and Jenkins 2002)
- CBT (Graves 2003 Williamson et al 2006)
- Psycho-social intervention
- Input from a Nurse specialist

Summary-Quality of Life is

- Integral to cancer and palliative care
- The psycho-social and personal needs of
 - The patient
 - Family
 - Friends
- Psychological therapies are a core part of treatment – adjuvant to medical and surgical treatments

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Conclusion

- Quality of life now on every agenda
- Clinicians and Nurses can do much to assess and improve QOL
- Patients are in the driving seat
- What is important to the team may not be as important to the patient
- Psycho-social interventions need to be utilised
- On going Evaluation is essential