Psychological Issues in Cancer Survivorship

Dr Andy Ashley
Clinical Psychologist
South Worcestershire Specialist Palliative Care, 2015
Introduction

• Cancer deaths are due to fall dramatically by 2030 with many more people expected to survive

• However, this doesn’t mean people are being cured: living longer with the disease which continues to impact on them

• National Cancer Survivorship Initiative (2008).
  • 60% have unmet psychological or physical needs
  • 30% have problems with close relationships
  • 90% have suffered financially
Psychological Challenges

• Anxiety: will the disease re-occur, fear of dying

• Dealing with the end of treatment

• Impact on your memory/ cognitive abilities

• Fatigue (getting extra sleep often doesn’t help)

• Stress responses: irritability, poor, sleep- 1/3 suffer PTSD type reactions

• Impact on relationships
What they said..
(Throwing light on the consequences of cancer and its treatment, Macmillan 2013)

‘For me, it is the psychological and emotional effects of the cancer that has affected me the most. I was diagnosed when my son was 7 months old and my nights were spent crying in bed that I was going to die and he would never know me and that my husband would be left alone to cope.’
Female, breast cancer, 5 years after diagnosis

‘I [don’t] have the energy for [my] day-to-day lifestyle. Pre-cancer people seem to live life in the fast lane, whilst you feel as if you are on the outside looking in.’
Female, breast cancer, 5 years after diagnosis
‘Although I was 65 when diagnosed, I was newlywed, the hormone treatment ruined our sex life and we found this extremely upsetting and difficult to live with especially my wife who still gets very upset. A less strong relationship could have split up.’

**Male, prostate cancer, 2 years after diagnosis**

‘Well, I had to get all my teeth removed before the radiotherapy and I found that completely devastating. I wasn’t prepared for it, it was just a case of, ‘You’re going to the dentist to get your teeth checked,’ and I thought, ‘Fine.’ Then all of a sudden somebody said to me, ‘Okay, all your teeth have to come out, cheerio.’ I found that worse than being told I had cancer for some reason.’

**Female, head and neck cancer, 2 years after diagnosis**
Anxiety of Re-occurrence

• Tends to subside in time as people feel stable, however certain events, e.g. hospital visits, pain, smells can trigger bouts of anxiety

• For some it affects them everyday, with worry thing thoughts popping in all the time. I can lead to hyper-vigilance, avoidance and irritability. Some have ‘biological symptoms’

• They are at higher risk of developing a secondary primary cancer

‘I do have a fear of dying and [the] cancer returning (I seen what it did to my mother!) and I would have liked someone to sit down with me for 10 minutes and explain what’s happening and can happen.’ Male, non-Hodgkin lymphoma, 1 year after diagnosis
End of treatment

• After diagnosis often people move quickly into treatment, this leaves little time to process things and brain focused on many immediate and difficult decisions to be made.
• Come to terms with the losses they are left with
• A very tiring journey, can be exhausted
• Less occupied, less support, more uncertainty, time to ruminate
• Doesn’t feel right you should be down- everything’s going well (incongruence of feelings)
• Not feeling able to fulfil bargains made during the illness
• Managing your own and others expectations
• Don’t want to talk about cancer to protect others
• However, can lead to low mood and isolation
• Worry that if you talk about things you’ll lose control
• People can take over, this is often helpful when you’re ill but not when you feel better and want to return to taking kids to school, cooking dinner, buying shopping etc
• Difficult to be frank as you don’t want to hurt others- but don’t want to talk about it all the time
• Can feel like the onus is again on you to make it right for others
• Being superwoman: I can do it all, not recognising you have an illness, doesn’t necessarily model to others they can talk about how they feel
Psychological Theory

- Murray Parkes, Kubler Ross: Stage theories around loss/dying, e.g. denial, anger, bargaining, depression and acceptance

- Normal process to move between these stages

- Denial is initially a helpful process, maintains existing model of world and usually short lived. It usually fluctuates

- Avoid confronting it unless it having a detrimental impact
Adjusting to Change

- James Brennan- Social Cognitive Transition Model (SCT) developed in relation to cancer

- we have a life trajectory, attachments, body, self and existential beliefs and when ‘faced with events that violate our expectations and assumptions we require a period of ..adjustment while our mental models ..assimilate what has happened’
Adjusting to Key Transitions

- Engaged in life to being a full time patient
- From being a well person to an ill one
- From feeling time was unlimited to knowing it is finite
- From being fully able to being disabled
- From looking one way to feeling disfigured
Spend five minutes thinking about your:

- Life trajectory: what is important in your life/ your plans and hopes for the future (write down three hopes, one per post-it)

- The key relationships in our lives

- The importance of our body to our lives: our energy, physical nature, how we look

- Beliefs about the nature of our existence/ why are we here/ what happens when we die
Coping with Stress

- Lazarus and Folkman (1984) suggested there are two types of coping responses: **emotion focused** and **problem focused**:

- Emotion-focused coping involves trying to reduce the negative emotional responses associated with stress such as embarrassment, fear, anxiety, depression, excitement and frustration.

- Problem-focused coping targets the causes of stress in practical ways which tackles the problem or stressful situation that is causing stress, consequently directly reducing the stress.
What Will Help?

1) Ask them about their emotional/psychological needs
   - 20-47% of people newly diagnosed and recurrent cancer patients show a significant level of distress
   - One study reported half of patients' surveyed experienced distressing, horrible or excruciating pain in the last 24 hours and a half had not spoken about it
   - Less than 1/2 of distressed patients are referred for psychological help

2) Are there things that can encourage problem-focused coping, e.g. taking more control of their situation. Perhaps providing information to help them/problem solving
Other helpful tips..

3) Can we help someone to grieve for their losses. It's ok to be upset (counter the myth that you need to keep positive to survive). Using a model, like the grief wheel to talk about change.

4) Often just knowing that what you’re experiencing is normal/ not pathological is hugely relieving. You’re not going mad. Are their support groups to help people with your cancer

5) Worry can initially be helpful as it helps us process information and problem solve- find solutions to difficulties we face (re-framing)
Things to Assess

- As part of an interview I would want to gauge their
  - Social support
  - Financial circumstances
  - Pre-existing mental health condition
  - How they have coped with other difficult situations in their lives, including dealing with loss
  - How did they feel about their diagnosis/ how have they reacted to scan results/chemotherapy
  - How do their family communicate
Case Study

- 59 year old woman who had a diagnosis of colon cancer with liver metastases. She had previously been an independent and active woman, working in a professional capacity. She had successfully completed chemotherapy and a scan had shown her tumours had shrunk. However, during a recent appointment six months after diagnosis she was low in mood and at times was angry. On further, exploration she reported having a lack of energy to get up and down the stairs, had pain in hands and feet which made it difficult to hold things. She was also concerned she had lost weight and looked different.

- Can you tell me what you might do to help, given some of the psychological theory we’ve talked about
Self reported strategies people live well with incurable illness

Living positively with incurable cancer, April 2014

- Breaking the future down into small goals
- Not looking too far ahead
- Try taking some control back into your life - establishing a routine
- Keeping ‘hope’ – e.g. ‘there is a very slim possibility I may return to work’
- It’s ok to feel upset - permission to cry - mourn for losses
- Being aware that others aren’t good at dealing with stress/anxiety - it doesn’t mean they don’t love you
- Humour - if you can’t laugh you will cry
- Helping others

Living positively with dementia, June 2013, Couples group

- Keeping occupied/ exercise
- Focusing on what you can do not can’t
- Make an effort to get out
- Have something to look forward to
- The person with dementia to keep involved
- Live for each day
- Take control of your situation
- Forget arguments/ don’t hold a grudge
- It’s ok to have a shout or cry
- It’s normal to find it difficult
- Sense of humour
- The person is not to blame for their illness