



The psychosocial impact of cancer on women with secondary breast cancer in a long term supportive-expressive group

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Overview

Presenting on the psychosocial impact of living with secondary breast cancer on women, partners & families

- based on 17 years experience
- delivering an innovative clinical service
- specifically for women with secondary breast cancer
- in Queensland, Australia.

Findings are based on data from 6 monthly self report questionnaires, as well as clinical experience working with this population.



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What do we mean by...?

Psychosocial impact

- psychological morbidity – depression, anxiety, trauma
- impact on relationships with family & friends
- physical symptoms as result of Rx and disease – fatigue, pain, insomnia etc.
- economic impact – inability to work, financial burden of Rx

Secondary breast cancer

- also known as metastatic, advanced, Stage IV – incurable disease

Supportive-expressive group therapy SEGT

- group intervention pioneered by Yalom and Spiegel in 1970/80s, further developed by Spiegel in 1990s at Stanford University with women with metastatic breast cancer



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Breast Cancer in Australia/Queensland

All breast cancer

- Estimated 1 in 8 women diagnosed in lifetime
- 15,166 women in Australia/3000 women in Qld diagnosed each year
- 69% cases diagnosed in women aged 40-69 years*
- 2892 women in Australia/500 women in Qld die each year
- 89% 5-year relative survival between 2006-2010**

Secondary breast cancer

- Exact number not known
- one third of women with primary breast cancer will go on to develop metastatic breast cancer
- Only one in five will survive longer than 5 years***



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What do we already know about...?

Supportive-expressive group therapy SEG T

It has been shown in randomised controlled trials RCTs to

- ameliorate emotional distress (Classen et al., 2001; Goodwin et al., 2001; Spiegel, Bloom, & Yalom, 1981)
- improve coping (Spiegel et al., 1981)
- reduce pain and fatigue (Goodwin et al., 2001; Spiegel & Bloom, 1983; Spiegel et al., 1981)
- improve QOL, ameliorate and prevent DSM-IV depressive disorders, reduce hopelessness and trauma symptoms, and improve social functioning (Kissane et al., 2007)

after 12 months in group, despite deteriorating physical health over time.



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Description of service

- Specialist clinical service, unique and innovative
- Established in 1999 as face to face group, evolved into a Statewide service, in response to perceived need
- Community based service, delivered statewide from Brisbane
- Weekly professionally led group, meets 1.25 hours pw
- Since 2001 delivered by telephone and face to face throughout Queensland, Australia
- Innovative adaptation of Supportive-Expressive Group Therapy
SEGT



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Description of service

- Slow open group with rolling recruitment over time
- Connects urban and rural women, partners and families
- Run by two therapists trained in group psychotherapy, with over 30 years clinical experience
- Biannual workshops for women, partners, family members
- Website, Facebook and DVD resources
- Peer Moderated online forum



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Description of service – weekly group

- Women are assessed individually prior to joining the group, by telephone or face to face
- Include partners or significant others in initial meeting
- Referrals from range of sources – brochures, posters in oncology units; website; oncologists or BCNs; Cancer Council Helpline, other women
- Since 2001 evaluated effectiveness of the group via battery of self report questionnaires, extended battery in 2005
- Outcomes are similar to published studies of RCTs with SEG.T.



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Participants (n = 49)

Between August 2001 and September 2014:

- 89 women joined the group and completed baseline questionnaires
- data of 40 women were excluded because they died (21), withdrew (15) or did not complete questionnaires (4) within first 12 months after joining.

Final sample of 49 women:

- Mean age = 51.60 years ($SD = 9.2$ years, range 23.86 – 69.05 years)
- Median time since diagnosis primary breast cancer = 40 months ($M = 59$ months, $SD = 57.50$ months)
- Median time since diagnosis secondary breast cancer = 18 months ($M = 9$ months, $SD = 22.56$ months)

* 12 participants (24.49%) diagnosed with secondary breast cancer at first diagnosis



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Participants (n = 49)

Relationship status:

- 37 women (76%) married or in defacto relationship
- 9 women (18%) divorced, separated or widowed
- 3 women (6%) single

Dependents:

- 29 women (59%) had adult children
- 7 women (14%) had children 18 years of under

Metastatic sites:

- Bone 90% Liver 33%, Lung, 16%, Brain 8%, Other 4.08%

Place of Residence:

- 22 (45%) lived in Brisbane
- 18 (37%) lived in rural or regional towns 200 – 1500kms from Brisbane (10 coastal towns, 4 properties/farms, 4 inland towns)
- 9 (18%) lived 100 – 200 kms from Brisbane



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Measures

2001 – 2014 (Sample n = 49)

Affect Balance Scale ABS (Derogatis, 1996) measures positive and negative affect states

Impact of Event Scale IES (Horowitz, Wilner, & Alvarez, 1979) measures subjective distress (intrusive and avoidant stress responses)

2005 – 2014 (Sub sample n = 22* completed all measures)

Profile of Mood States POMS measures 5 negative moods states

EORTC-QLC30 (Quality of life questionnaire)* assesses physical, psychological and social functioning

Mini MACS (Mental adjustment to cancer scale) (Greer & Watson, 1989) ** reflects specific coping style

Social Provisions Scale SPS assesses social relationships and support

Family Assessment Device FADS a measure of family dynamics

** cancer specific measures



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Results

Trends over time in this group

- significant reduction in negative affect and increase in positive affect (ABS) (O'Brien et al., 2008)
- significant reduction in trauma symptoms (IES) after 12 months in group
- benefits gained after 12 months are maintained (trauma symptoms on IES) or further improved (negative affect on ABS) after 2 years in group



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Results

- all negative mood states, except fatigue, improved after 12 months (POMS) but not significantly
- physical health and role functioning of women worsened over first year in group, but emotional, cognitive and social functioning remained resilient (EORTC-QLC30)
- women were significantly more likely to show 'fighting spirit' than avoidant attitudes; there was a significant reduction in 'anxious preoccupation'; and 'hopelessness & helplessness' was the least likely coping response (MiniMAC)
- Social support (SPS) and family functioning (FAD) in normal range at entry



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Discussion – Psychosocial impact

Psychological morbidity

- women present with high levels of distress (depression, anxiety and trauma symptoms) (IES; ABS; POMS)
- experience significantly more intrusive stress symptoms, less avoidant (IES)
- want help to make sense of the diagnosis - more likely to show 'fighting spirit' and 'fatalism' than avoidant coping responses or feel 'helpless/hopeless' (MiniMAC)
- report feeling devastated by diagnosis



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Discussion – Psychosocial impact

Psychological morbidity

- 25% women diagnosed with secondary breast cancer at outset feel cheated of chance to beat the cancer
- women feel isolated and want to know how other women cope
- rural women are doubly isolated – less access to specialist & supportive services
- feel don't belong in support groups for women with primary breast cancer and “invisible” or “forgotten” in focus of ‘pink’ movement



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Psychosocial impact

Impact on partners, families, relationships

- Family dynamics in normal range (FAD); social support & engagement improved after 12 months in group (SPS)
- 75% women are married or in committed relationship – socially connected
- Through 10 years experience of conducting a parallel partners group – partners feel it's “not their time”; some struggle to accept and cannot talk about fear of death and dying



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Psychosocial impact

Impact on partners, families, relationships

- Women express fears about leaving their children without a mother, or to be raised by another woman; of not seeing their children grow to adulthood and have children of their own
- Some women make videos, baby clothes, write stories and create memory boxes for their children and the grandchildren they may never see
- Within families often fear of burdening each other
- Role of group and workshops to encourage sharing of feelings and experience.



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Psychosocial impact

Impact of disease/treatment

- QOL & role functioning (work etc) significantly worsened in first 12 months (EORTC)*; insomnia significantly increased
- Treatment ongoing and never ends
- Burden of physical symptoms, pain and fatigue cannot be underestimated
- Regular 3 -6 monthly scans and blood tests to monitor progression generate anxiety – women refer to it as a rollercoaster ride



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Psychosocial impact

Impact of disease/treatment

- Side effects often worse than disease itself
- Every progression is devastating as it moves women closer towards death
- Successive losses – in health, capacity to work and participate in daily living
- Death of women in the group while confronting also provides opportunities for growth; helps women prepare for their own death and learn from others



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Psychosocial impact

Economic impact

- Illness imposes significant financial burden on women and families – loss of work, loss of income (including partners), difficulties accessing superannuation, cost of pharmaceuticals and medical interventions, for rural women additional costs of travel & accommodation to access treatment (EORTC)

Additional benefits of the group

- Supports women to adhere to debilitating anti cancer treatments
- Women become active participants in their treatment; seek information about their disease and communicate with treating doctors; seeking second opinions, clinical trials etc.
- Most women end their lives with a peaceful ‘good’ death – not caught out or frightened



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Conclusions

- Psychotherapy research has consistently demonstrated that groups are as effective as individual therapy
- Meta-analyses have shown that group therapy is more effective than individual therapy in alleviating anxiety and depression in cancer patients (Sheard & Maguire, 1999)
- Kissane's Australian RCT of SEGTP with women with metastatic bc (2007) found DSM –IV depressive disorders were ameliorated and prevented



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Conclusions

- Despite evidence of benefit, in Australia at least, there are few professionally led groups specifically targeting women with secondary breast cancer
- Our adaptation of SEGT is an intensive specialist intervention – some cost to deliver – but targets the most distressed women in this population
- Benefits of improving QOL, helping women and partners and families to live meaningful lives in the face of this frightening and debilitating illness, attests to the importance of providing more groups of this kind in Australia and elsewhere.



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Where to from here?

- Plans to extend the service through holding regional workshops in conjunction with local health professionals to reach more women, partners and families affected by secondary breast cancer
- Promote our group model through training of health professionals interested in delivering groups of this kind
- Currently making a new documentary resource for women, partners, families and health professionals to improve awareness and understanding of the needs of women with secondary breast cancer - this 'forgotten' and under researched population



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