

Therapy with women with metastatic breast cancer

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Objective: To describe some clinical issues encountered in individual and group therapy with women with metastatic breast cancer.

Conclusions: The pressure to 'keep positive' poses dilemmas for patients and therapists alike, whether in individual or group therapy. The basis of skilled supportive care rests on the ability of therapists to assist patients and their families to face death rather than avoid it. Paradoxically, facing issues of death and dying leads to a greater sense of control, and empowers patients to reorder life's priorities, thus improving quality of life and relationships. In addition to the obvious need to detect and treat illness such as depression, working with women with metastatic breast cancer requires flexibility on the part of the therapist to adapt to her physical state of health, to include partners and family members where possible, and to liaise with colleagues in the treating team to facilitate communication and understanding of specific difficulties that may be encountered.

Key word: breast cancer.

Breast cancer is the leading cause of death for women in Australia, accounting for approximately 2600 deaths per year.¹ The emotional impact of the diagnosis of metastatic disease is profound, 78% of women considering it more distressing than the original diagnosis of breast cancer.² Given the prevalence of messages from friends, family and the media that 'positive thinking' will influence disease outcome, the woman whose disease has progressed is likely to feel overwhelmed with guilt and self-recrimination. In essence, she is judged to have 'not tried hard enough'. Her thoughts turn to her family 'How will they manage when I'm gone?' and regrets about lost opportunities 'I'm not ready to die – I have more living to do!' However, when she attempts to discuss her innermost thoughts and fears with others, she often receives platitudes, leading to a powerful sense of isolation and despair.³ Compounding this emotional distress is the need to cope with symptom burden and the demands of medical appointments and treatments, often underpinned by financial strain. Concerns about body image changes secondary to the disease and treatment may seem trivial in the context of metastatic disease, but the strong sense of being betrayed by one's own body and no longer being oneself is summed up in the words: 'When I look in the mirror, I don't see me'.

WHAT IS AVAILABLE TO HELP WOMEN WITH METASTATIC BREAST CANCER?

Individual therapy

The concept of demoralization provides a useful framework for assisting women with metastatic breast cancer, and exploration of the meaning of the diagnosis, especially as this resonates with past experiences of loss and grief, is often central to individual therapy. Provision of symptom relief, attention to cognitive distortions, assistance with problem-solving, and encouragement of realistic goal-setting all underpin the provision of a 'safe' and supportive environment in which the therapist 'shares the space' with the woman.⁴

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However, at times the therapist may experience tension between empathically responding to the existential concerns of the woman, and the powerful wish to alleviate distress. Although depression is common in women with metastatic breast cancer,⁵ it is important to reflect when prescribing antidepressant medication, 'Is this for the patient, or for me?'

Working with a woman with metastatic breast cancer often necessitates a flexible approach, responsive to her physical status and the demands of treatment. This is exemplified by the case of a mother of three teenage children whose condition deteriorated the evening before a scheduled appointment with her and her husband. Her husband rang and asked if his sister could attend in their place. The consultation, in which many emotionally charged issues were discussed, was taped. A follow-up phone call revealed that the whole family had listened to the tape while sitting on the woman's bed, this providing a springboard for a rich and moving sharing of feelings.

The needs of family members may emerge and exert a major influence on the adjustment of the woman, such that direct contact with, and support of, family members is often necessary. This is typified by the case of a 53-year-old woman whose family was angry and resentful about the perceived delay in the diagnosis of metastatic disease, and guilty that they had not played a more active role in the investigation of symptoms. Their repeated requests to 'keep on with treatment' despite the woman's admission to hospital in a highly debilitated state were intensely distressing for the ward intern. Gentle reflection with her husband about the closeness of the marital relationship, explicit statements by the therapist that his wife trusted him implicitly, and the therapist's conviction that she would never feel he had let her down 'no matter what' provided a chance for the family to 'let go'. The woman's treatment was ceased and she died peacefully the next morning.

Awareness of the medical status of the woman is also important. The terminally ill woman who announces that her daughter is planning her wedding for 12 months' time may be indirectly asking: 'Will I be here?' Exploration of her fears and uncertainties may be difficult, but will model for the woman the possibility of confronting difficult realities and thus enable more open communication within the family. It is important for the therapist to be cognizant of the impact of decisions on family members, and the potential for regret after the woman's death about things left undone. For the daughter in this situation to be deprived of her mother's attendance at her wedding is a major blow, and only through open communication can the family make plans that accommodate the likely course of disease, and make the most of the moment.

Another, perhaps less obvious role in therapy is liaison with, and support of, medical staff who may find themselves the target of expressions of intense or unexpected

anger from patients. For example, one woman who had coped with her rigid and affectionless childhood by becoming extremely independent and self-sufficient, described feeling betrayed by the diagnosis of metastatic disease, just as she had felt betrayed as a young girl to learn of her mother's infidelity. Furthermore, her pride in her work achievements and the notion that she could be 'the best mother' were challenged by the diagnosis, which exposed her fears that in fact her family was not 'perfect', nor would she achieve such a state before she died. Her despair was initially expressed as criticism of the medical staff treating her. Discussion with medical colleagues in such cases can help them to understand and appreciate the woman's responses and accommodate her concerns, rather than feeling attacked or defensive.

Group therapy

The support groups traditionally offered for women with breast cancer encourage positive thinking and aiming for the future. However, such groups can pose a problem: women who hope to survive find the presence of women with metastatic disease discomfiting, and the women with metastatic disease feel silenced by the fear that they and their questions generate. Supportive-expressive groups designed for women with metastatic disease have provided a safe forum for the expression of emotions, and to both give and receive support.

Keen attention has been paid to supportive-expressive groups in cancer in light of a 10 year follow-up of a Stanford study in which the 50 women with advanced breast cancer in the experimental group were found to live on average twice as long as the routine care group.⁶ That study also demonstrated that, compared with the control group, women who participated in the supportive-expressive group were less anxious and depressed, and had less pain. While a survival advantage of participation in a supportive-expressive group has been replicated in five out of 10 later studies, the findings of reduced depression and pain appear robust.⁷⁻⁹

The approach adopted by Spiegel, who trained with Yalom (a pioneer of group therapy with the medically ill), was radically different from the typical medical one.¹⁰ He urged the women to face cancer rather than wish it away, and to reorder life's priorities. His aim was to help people take control and hence enhance the quality of their lives by 'living beyond the limits the illness imposed'. The seven components of treatment that he found to be crucial in diminishing psychosocial distress were: social support, expression of emotion, detoxifying dying, reordering life's priorities, family support, effective communication and symptom management.¹¹

In Australia, a supportive-expressive group for women with metastatic breast cancer was conducted in Melbourne until 2003 as part of a double blind randomized controlled trial. That group continues to meet at Box Hill, Melbourne, with a growing membership.

Since 2001, a weekly clinical group has been established in Brisbane, using a mixed format of audio-teleconferencing and face-to-face meetings. Both groups are largely unstructured and slow open groups, so women can be admitted throughout the life of the group, thus maintaining the group's viability. The therapists' interventions are primarily supportive or designed to encourage expression of often painful feelings. Some interpretations are made but the therapists' function is predominantly containing. Interventions may help the group face difficult issues when something is being avoided, or facilitate cohesion by drawing attention to similar experiences or difficulties within the group.

In the groups, fear of death is commonly expressed. One group member stated that *'Just creeps up – we have to confront it and take control'*. Death is not what they fear, but how they die, and the importance of maintaining dignity and respect at the time of death is often discussed. Through the group the women are able to think about ways to open discussion with their families and friends in order to prepare them for a future without them.

Another commonly expressed theme is the way external appearance can belie inner feelings of despair and the inability to speak of this, in part for fear of being seen as a fraud, but also because of the overt pressure to *'keep positive'*. Group members speak about the group enabling them to overcome the marginalization and isolation resulting from the diagnosis of metastatic breast cancer. In the group, there is relief about *'not being the only one'*, and being able to talk openly and freely about death and dying without fear of upsetting others or being told to be positive. The social benefits of the group often extend to opportunities for partners and children to meet. Attendance at funerals by group members and group therapists on occasions has been an important part of the group's commemoration of a woman's life and death.

The teleconferencing component of the Brisbane group was to provide access to the group for women from rural and remote areas. Women joining this group were asked to provide a story about themselves, and a photograph for circulation to all members of the group. These photographs, as well as the occasional face-to-face contact made when rural members came to Brisbane, helped to put faces to names and made for more meaningful interactions. The sharing of emotion and experience can be very beneficial, as typified by the case of an isolated rural woman who was encouraged by the group to seek radiotherapy as an alternative to increasing morphine, which caused her to sleep most of the day. Following radiotherapy, she was able to significantly reduce her morphine with corresponding improvement in the quality of her life. An additional advantage of teleconferencing is that it allows women to access the group when they are sick or in some cases in hospital receiving treatment. One notable example was a woman who used to call into the

group from the oncology department while receiving chemotherapy. A number of women participated in the group until approximately 3 weeks prior to their death. For rural women, the telephone link to the group has been dubbed *'a lifeline'*.

Data from the Melbourne group are still being collected. Qualitative data from the Brisbane group have yielded similar themes to those described by Spiegel and Glafkides,¹² suggesting that the mixed mode of delivery has neither diluted nor diminished the value of the group.

CONCLUSION

The psychological concerns of women with metastatic breast cancer are complex, and in an era when anyone can describe themselves as a therapist, it is important that psychiatrists, psychologists and social workers do not re-sile from promoting the very real skills conferred by their training. Dr Spiegel's view is that the quality of the group therapists' training and their experience relates directly to the success of the group (pers. comm., 2003). Psychiatry and other mental health professions have a role to provide leadership in advocating for equitable access to flexible, timely and skilled supportive care, based on a thoughtful approach to the woman's needs, rather than the popular approach of *'one size fits all'*. Clinical work with women with metastatic breast cancer is interesting and profoundly rewarding, and affords the opportunity to learn about the process of living and dying, and even more about oneself.

My Dancing Flame

*To me you will always be a glistening candle.
Your glowing love fills me with warmth and a feeling of
security.
I stare into the dancing flame, its movement is so unpredictable,
yet despite its ever changing directions, it remains bright,
with sparks of optimistic images of what the future may hold.
Your light radiates through my body filling me with energy,
and a sense of hope and happiness.
This shining light guides me on my journey of life.
Although this glistening candle cannot shine forever.
As the wick wears down, life itself drips slowly away.
I watch the burning wax melt away,
each piece evidence of a fulfilled, beautiful existence.
The flame has gone and I am mourning.
Tears flow down my pale white face,
I struggle amongst the dark and gloomy smoke.
Suffocating, I need the light, I need the warmth.
I feel I cannot get past this smoke, I cannot exist alone.
Then the smoke has cleared, I begin to finally walk away,
I accept the challenge.
I realize that this flame is still alight in my heart,
It will remain within my soul,
a dancing spirit which I will love, I will admire, I will appreciate,*

and I will treasure in the passing of today and the coming of tomorrow.

Written by Andrea Sertori (15 years) in dedication to her mother Helen, published in *A life to live: a group journey with advanced breast cancer*, The Thursday Girls 2004, PsychOz Publications, Melbourne, Australia, p. 3.

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