Living with advanced breast cancer in women resilient to distress versus women with persistent distress: a qualitative study

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KEY MESSAGES

1. Cognitive bias in information, thought suppression, social constraints, and pre-existing exposure to life stress were potential risk factors for chronic distress in response to advanced breast cancer.
2. Patients with advanced breast cancer should be assessed for recent exposure to life crises, quality of available family support, and pre-existing emotional problems. Timely referral for relevant supportive services should be implemented.
3. Patient support groups should be introduced to patients in the early phase of breast cancer.
4. Response style and cancer-related rumination should be assessed in women with breast cancer. Early referral to manage maladaptive rumination should be implemented to prevent chronic distress.

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Introduction

Improved treatment options have increased survival in women with advanced breast cancer. However, the incurable and progressive nature of the disease makes enormous emotional demands of women living with advanced breast cancer. Yet, most women with locally advanced or metastatic breast cancer have been reported to show little distress; only one in ten have been reported to show persistent distress over time.[1] Understanding the factors that differentiate individuals on distinct distress trajectories is essential to inform therapeutic interventions. Personal attitudes towards and meanings of disease influence how an illness is embodied, lived, and coped with and in turn dictates adjustment to that illness. Hence, construction of illness meaning may play an important role in differentiating women with persistent distress from those with low or transient distress. The present study aimed to compare women with persistent distress and those with low or transient distress in terms of illness meaning of advanced breast cancer and how illness meaning influences their coping strategies. The following questions were addressed: (1) What does being diagnosed with advanced breast cancer mean? That is, how do women fit the diagnosis of advanced breast cancer into their individual life schema? (2) How do the meanings ascribed to advanced breast cancer shape the affected individuals' coping strategies?

Methods

To compare women with persistent distress and those with low or transient distress in response to advanced breast cancer, a sample was drawn from our existing longitudinal study to explore trajectories of psychological distress over the first year following diagnosis of advanced breast cancer. A total of 42 Cantonese- or Mandarin-speaking Chinese women who were diagnosed with locally advanced or metastatic breast cancer and received care from public oncology centres were recruited (Table). Interviews were recorded, transcribed, and analysed following grounded theory approaches using simultaneous analysis.

Results

Narrative analyses identified several distinct characteristics that differentiate women with persistent distress from those with low or transient distress: (1) living through ongoing life crises, (2) information processing bias, (3) thought suppression, and (4) sense of demoralisation. These distinct characteristics were not mutually exclusive but highly interrelated.

For women with persistent distress, the diagnosis of advanced breast cancer was often viewed as another blow in life. A common, distinct feature in women with persistent distress was dealing with ongoing life crises, such as caring for

TABLE. Characteristics of the participants

Case No.	Age, y	Marital status	Occupation	Education	Diagnosis	Distress pattern	Recurrence
1	48	Divorced	Unemployed since diagnosis	Secondary	Non-metastatic	Low	No
2	49	Married	Employed	Secondary	Non-metastatic	Low	No
3	38	Married	Employed	Tertiary	Non-metastatic	Transient	No
4	39	Married	Employed	Tertiary	Non-metastatic	Low	No
5	39	Married	Employed	Tertiary	Non-metastatic	Transient	No
6	53	Married	Unemployed since diagnosis	No education	Non-metastatic	Low	No
7	46	Married	Unemployed since diagnosis	Secondary	Non-metastatic	Transient	No
8	40	Married	Employed	Secondary	Non-metastatic	High	No
9	42	Married	Unemployed since diagnosis	Secondary	Metastatic	Low	Yes
10	59	Married	Employed	Tertiary	Non-metastatic	Low	No
11	47	Married	Homemaker	Secondary	Non-metastatic	Transient	No
12	51	Married	Homemaker	Tertiary	Non-metastatic	Transient	No
13	45	Married	Homemaker	Secondary	Non-metastatic	Low	No
14	45	Divorced	Employed part-time	Tertiary	Non-metastatic	Low	No
15	40	Single	Employed	Secondary	Non-metastatic	Low	No
16	67	Widowed	Retired	Secondary	Metastatic	Low	Yes
17	48	Married	Employed part-time	Tertiary	Non-metastatic	Low	No
18	49	Married	Homemaker	Primary	Metastatic	High	No
19	47	Married	Unemployed	Tertiary	Metastatic	Low	No
20	44	Married	Unemployed	Primary	Non-metastatic	High	No
21	50	Single	Employed	Secondary	Metastatic	Transient	No
22	67	Married	Unemployed since diagnosis	Primary	Metastatic	Low	Yes
23	73	Married	Homemaker	Primary	Metastatic	Low	Yes
24	53	Married	Unemployed since diagnosis	Primary	Metastatic	High	Yes
25	58	Married	Retired	Secondary	Metastatic	High	No
26	35	Married	Employed	Tertiary	Non-metastatic	Low	No
27	30	Single	Employed	Tertiary	Non-metastatic	Transient	No
28	52	Single	Unemployed before diagnosis	Secondary	Non-metastatic	Low	No
29	40	Single	Employed	Secondary	Non-metastatic	Transient	No
30	60	Married	Homemaker	Primary	Metastatic	Low	Yes
31	48	Single	Employed	Secondary	Metastatic	Low	No
32	57	Married	Employed	Secondary	Non-metastatic	High	No
33	47	Married	Homemaker	Secondary	Metastatic	Transient	No
34	58	Widowed	Employed	Primary	Metastatic	Transient	Yes
35	46	Married	Employed	Secondary	Non-metastatic	Transient	No
36		Married	Homemaker	Secondary	Metastatic	Transient	Yes
37	53	Married (husband died during the study)	Unemployed after diagnosis	Secondary	Non-metastatic	High	No
38	53	Married	Unemployed after diagnosis	Primary	Metastatic	High	No
39	43	Widowed	Unemployed after diagnosis	Secondary	Non-metastatic	High	No
40	47	Married	Unemployed after diagnosis	Secondary	Non-metastatic	High	No
41	47	Married	Unemployed since diagnosis	Tertiary	Metastatic	Transient	Yes
42	46	Divorced	Homemaker	Primary	Non-metastatic	High	No

family members with chronic or terminal illness, loss of spouse, marriage failure, or work stress.

> *"I was very upset (about the diagnosis). I asked myself, 'Why is this happening to us'? My husband was diagnosed with lung cancer. Now it's me.... His condition has been stable for a while. After I got sick, his condition got worse. When I was having chemotherapy, his condition deteriorated rapidly and he was hospitalised. I had to look after him when I was having chemo. He was very picky. Apart from me, he wouldn't let anyone else feed him.... At one time, I said to my husband, 'Perhaps we should just end our life together'. It was just a thought, of course. We had to keep it going.... After I finished the radiation therapy, my husband passed away. It was very, very hard..." (case 37)*

Owing to their chronic ongoing life stress, these women often had pre-existing emotional problems. Some had previously sought help from psychiatrists or clinical psychologists but were in remission before the cancer diagnosis. The cancer diagnosis triggered relapse of the emotional instability.

> *"My former job was very stressful.... I was also very anxious. I always thought, 'why is my life so bad'? It's so unfair. I was referred to a psychiatrist. The doctor gave me some medication." (case 39)*

Another characteristic of women with persistent distress was attentional and interpretational bias toward threat-related information. Although most women reported physical symptom distress, women with persistent distress expressed difficulties shifting their thoughts away from the unmanaged physical symptoms. They often exhibited vigilant behaviour and intrusive cancer-related thoughts. Furthermore, they often interpreted these as signs of cancer recurrence or disease progression.

> *"I got very worried when I wasn't well about things like having pain. I couldn't help but keep thinking about it. It was very stressful. I felt helpless." (case 43)*

To deal with their intrusive thoughts, some patients attempted to suppress their thoughts by forcing themselves not to think about their illness and avoiding situations that reminded them about their illness.

> *"I don't want to talk about this (my illness). My life is a tragedy. I force myself not to think about it. Whenever I talk about it, I cry.... I don't join the activities organised by the cancer resource centre. I don't like to meet other patients with cancer. I don't want to be reminded about (my illness)." (case 42)*

Many patients with persistent distress exhibited demoralisation syndrome, including senses of hopelessness and helplessness, feelings of being trapped, and lack of motivation to cope effectively.

> *"I feel hopeless. There is no cure. There is no hope.... Just waiting. When it's time, that is it." (case 38)*

In contrast to women with persistent distress, women with transient distress adopted various strategies to cope with the demands of the illness, including acceptance, taking charge, and social support. Rumination on cancer and its impacts was perceived as ineffective for coping with the demands. Some patients refused to let the illness take over their lives. Instead, they proactively maintained their normal routines. In contrast to women with persistent distress who avoided social support from peers, women with transient distress viewed patient support groups as effective coping resources. Mutual sharing with other patients with advanced breast cancer helped these women come to terms with the diagnosis.

> *"I was very down when I found out that I need chemo. But it's only temporary. I didn't let myself think about it. I just focused on completing the treatment and getting on with my life."*
>
> *"I had to look after myself. I had to take charge. If I want to be healthy, I need to treat myself well." (taking charge: case 35) (acceptance: case 27)*

> *"I met so many patients like me. It made me realise that the disease is not as horrible as I thought. Now I know that having this illness doesn't equate to a death sentence." (social support: case 36)*

Women with low, stable distress shared common features with respect to coping with illness demands with those of women with transient distress. However, several additional features seem to be linked to their resilience, including living in the present and having a pre-existing stable, supportive family.

> *"I am not upset or scared. I don't worry. I try to live fully each day." (living in the present: case 04)*

> *"I am lucky that I have a supportive husband. I don't have to worry about my family." (supportive family: case 22)*

Discussion

The narratives of women with persistent distress highlighted how the illness permeates every aspect of their lives and often leads to a sense of demoralisation.[2] In contrast, women with low, stable or transient distress were able to encapsulate the illness with minimum impacts on their lives.[2] Cognitive biases in information processing were a key differentiating factor in women's illness representations. Women with persistent distress

were not only vigilant towards somatic and cancer-related threats but also had difficulties with disengaging from these threats. To cope with the perseverative negative thinking, cognitive avoidance was commonly used by women with persistent distress. These women acknowledged their inability to control their own worry and rumination, which prompted them to attain control over their negative thinking using thought suppression. This was counterproductive and resulted in increased levels of intrusive thoughts and attentional bias towards somatic and cancer-related information.

In contrast, women with low, stable or transient distress did not engage in dysfunctional repetitive thoughts. They were able to accept and/or live in the present moment, a component of mindfulness practice.[3] Mindfulness may reduce anxiety and depression symptoms among patients with cancer.[3] Hence, mindfulness-based intervention may be beneficial to women with persistent distress who have attentional bias toward cancer-related threats.

The role of social support (family and peer support groups) was also highlighted in the narrative analysis. Women with low, stable or transient distress received encouragement from their peers and families to adopt positive coping strategies. In contrast, women with persistent distress were often in unsupportive environments that likely promoted thought and emotion suppression.

Exposure to multiple life stresses was another differentiating factor. Previous or current life stress has commonly been reported in women with persistent distress, and they have been reported to be more vulnerable in terms of coping with cancer impacts.[4] Similarly, people who are depressed show selective recall of negative events.[5]

Conclusions

Cognitive processing, social resources, and exposure to life stress influence how women cope with advanced breast cancer. Cognitive bias in terms of information, thought suppression, social constraints, and pre-existing exposure to life stress were the potential risk factors for chronic distress in response to advanced breast cancer.

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References

1. Lam WW, Soong I, Yau TK, et al. The evolution of psychological distress trajectories in women diagnosed with advanced breast cancer: a longitudinal study. Psychooncology 2013;22:2831-9.
2. Nerenz DR, Leventhal H. Self-regulation theory in chronic illness. In: Coping with Chronic Disease: Research and Applications. Burish TG, Bradley LA, eds. New York, NY: Academic Press; 1983: 12-37.
3. Piet J, Wurtzen H, Zachariae R. The effect of mindfulness-based therapy on symptoms of anxiety and depression in adult cancer patients and survivors: a systematic review and meta-analysis. J Consult Clin Psychol 2012;80:1007-20.
4. Bonanno GA, Westphal M, Mancini AD. Resilience to loss and potential trauma. Annu Rev Clin Psychol 2011;7:511-35.
5. Mathews A, MacLeod C. Cognitive vulnerability to emotional disorders. Annu Rev Clin Psychol 2005;1:167-95.