



The Advanced Breast Cancer Group: Helping to improve psychological wellbeing and reduce distress

Women involved in the group are asked to complete a set of questionnaires, when they first join and every six months thereafter. These questionnaires are used to enquire about a woman's experience of living with secondary breast cancer. Responses are combined to form an overall snapshot of the group's physical, emotional and cognitive experiences. This data is analysed periodically to track women's progress over time and to indicate how helpful the group may have been for improving wellbeing and reducing distress.

Outcomes after 1 Year of Membership

Between 2001 & 2023, 61 women completed two questionnaires, the Affects Balance Scale (ABS) and the Impact of Event Scale (IES), at baseline (prior to joining the group) and after 12 months in the group. These questionnaires investigate mood and psychological distress. ABS results showed that after 12 months in the group there was a significant reduction in negative feelings (i.e., guilt, anxiety & depression), and slight improvements in positive affect. See Figure 1 for ABS results.

Analysis of the IES, which measures whether women tend to avoid thinking about the effects of the illness (i.e., Avoidance) or can't help themselves thinking about it (i.e., Intrusion), showed that after 12 months in the group there was a significant reduction in Intrusive stress response symptoms. While women in our group show a high incidence of both types of stress responses compared to individuals without cancer, our group members experience tend towards intrusive thoughts than avoidant thoughts. This tendency to respond to stress "head-on" may have been a factor for women joining the group to share their experiences of secondary breast cancer. See Figure 2 for IES results.

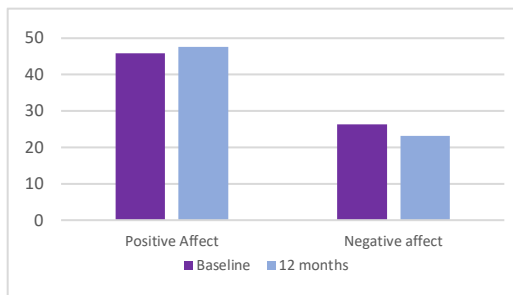


Figure 1. ABS Positive and negative affect (feelings) at baseline and 12 months.

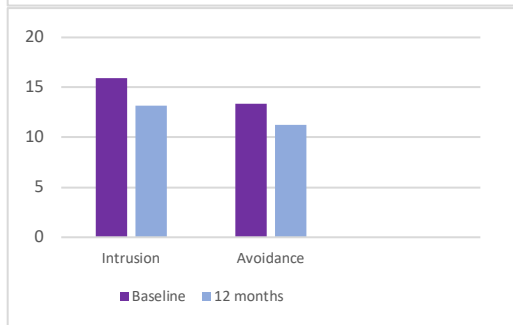


Figure 2. IES Intrusive and Avoidant stress symptoms at baseline and 12 months.

Outcomes after 2 Years of Membership

A smaller number of women (39) have now completed these questionnaires over 2 years. Analysis of outcomes after two years in the group has shown that in general, benefits gained after 12 months in the group have been maintained or in some instances further improved. On the ABS, we found a significant reduction in negative affect at 12 months compared to baseline and a further reduction in negative affect from 12 months to 2 years. Positive affect (feelings) was maintained from baseline to 12 months and then 2 years. See Figure 3.

Analysis of IES outcomes after 2 years in the group showed significant improvement in intrusive stress responses at 12 months, and these improvements were maintained in the second year. A significant improvement in avoidant stress responses after 12 months was also evident and this change was sustained after 2 years. See Figure 4 for IES results.

A subsample of the group have also completed five additional questionnaires. Please turn over to read a summary of these findings.

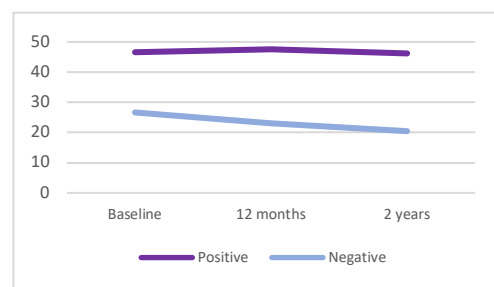


Figure 3. ABS Positive and negative affect (feelings) at baseline, 12 months and 2 years.

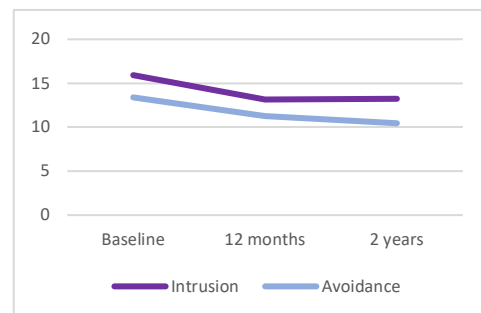


Figure 4. IES intrusive and avoidant stress symptoms at baseline, 12 months and 2 years.



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In 2005, we introduced five additional questionnaires which enquired about social and family relationships, quality of life, mood states, and how individuals cope with cancer. From 2005- 2023, 34 women have completed these questionnaires at both baseline and 12 months later.

Impact on quality of life (European Organisation for Research and Treatment of Cancer, Quality of Life Core 30 [EORTC- QLC30]):

The EORTC is designed to explore cancer sufferer's general health, as well as the physical, cognitive, role, emotional and social impacts the disease has on their day-to-day functioning. The results revealed that the women's overall health, as well as their ability to carry out their daily roles, significantly declined between when they joined the group and 12 months later. Further, fatigue had significantly increased as a symptom for these women during the 12 month period, and a substantial increase in insomnia was also evident. These results are not unexpected, given the sample population, and highlight the wide ranging impact cancer has on an individual's ability to continue carrying out their daily activities.

Mood (Profile of Mood States [POMS]):

The POMS measures five negative mood states (tension/anxiety; depression/dejection; anger/hostility; fatigue/inertia; confusion/bewilderment), one positive mood state (vigour/activity), and a total mood disturbance score. Slight (but not statistically significant) reductions in all of the negative mood states between baseline and 12 months were evident. A significant increase in fatigue/inertia was observed. Additionally, there was a small decline in vigour/activity. Given the impact on quality of life findings mentioned above, it is not surprising that women in the group reported struggling with fatigue and a decline in vigour/activity.

Coping styles (Mini-mental adjustment to Cancer Scale [MiniMac]):

The MiniMac has been specifically designed to assess how individuals react and respond with regards to living with cancer. When women first joined the group, it appeared that 'fatalism', which is characterised by putting oneself in the 'hands of God' and taking one day at a time, was the most common coping style. This continued to be the case 12 months later, however, there was also a reduction in 'anxious

preoccupation' over the same time period. That is, the degree to which the women adopted an anxious coping style decreased (but not in a way that was statically significant). At both times, the women in the group were least likely to adopt a 'helpless/hopeless' coping style. There was a slight reduction in the women's reports of "fighting spirit" at the 12-month period.

Social provisions obtained from relationships (Social Provisions Scale [SPS]):

The SPS measures six different social functions or 'provisions' that may be obtained from relationships with others. These include, 'attachment', 'social integration', 'reassurance of worth', 'opportunity for nurturance', 'reliable alliance' and 'guidance'. At entry to the group, women reported higher scores for reliable alliance and attachment (relative to other provisions), meaning they felt they could depend on others to look after them and that they had close relationships with loved ones. Over the next twelve months, however, guidance became the second highest provision, suggesting that receiving advice and information from sources such as the ABCG, was proving to be a crucial form of social support for these women. The results also showed a slight increase in the social integration provision over the 12-month period, indicating that the women may have been participating in a higher number of social activities compared with when they first joined the group.

Family functioning (Family Assessment Device – Global Functioning [FAD]):

The FAD global functioning subscale assesses characteristics that distinguish healthy and unhealthy family dynamics. The results indicated that women in the group experience healthy family functioning, which in turn, may positively affect their overall well-being, as well as their ability to live with cancer. They also showed that advanced breast cancer did not significantly impact the quality of their family function.

For a more detailed report about these findings, please visit our website: <http://www.abcg.org.au>