

Coping and the Experience of Adjuvant Chemotherapy for Early Breast Cancer

Results of the Research

We recently completed our research which aimed to investigate the way in which coping affected the levels of anxiety, depression and side effects experienced by women undergoing adjuvant chemotherapy for early breast or colo-rectal cancer. We are pleased to let you know that we have now calculated the results and have prepared the following report for you.

When we calculated the results, we compiled all of the participants' data and calculated the average experience of participants. This means that the results reflect what participants thought and felt *on average*, not what individual participants thought and felt. For this reason, it is possible that some of the results of the report do not reflect or are not relevant to your personal experience. Nonetheless, we hope they provide some valuable information for you. Please do not hesitate to contact us on the numbers provided if you would like to discuss the research in more detail.

Who participated?

The study aimed to recruit women who had been diagnosed with early breast or early colo-rectal cancer. Unfortunately, very few women with early colo-rectal cancer were interested in participating in the study. This meant we were not able to calculate the results for participants with colo-rectal cancer. The results presented in this report only focus on women with early breast cancer.

- Participants were aged from 30 to 70 years with an average age of 53 years.
- Most participants were partnered (66%) and the remainder were single (34%).
- Most participants lived in the ACT (79%) and the remainder lived in NSW (21%).
- Most participants completed university study (62%) and the remainder completed primary and/or secondary school (38%).
- Most participants were either employed (70%) or retired (28%).

- Participants attended hospitals across the ACT, including the Canberra Hospital, Calvary Hospital, the National Capital Hospital and John James Hospital.

What did participation involve?

Participants completed an interview with Sarah Davenport before starting chemotherapy treatment and a series of questionnaires throughout chemotherapy treatment and 6- and 12-months following the completion of chemotherapy.

The interview and questionnaire asked participants to comment on several aspects of their treatment:

- the way in which they coped with any difficulties related to their diagnosis and chemotherapy treatment
- whether they experienced any anxiety or depression symptoms
- whether they experienced any side effects from chemotherapy
- what participants thought influenced their disease (i.e. their own actions, the actions of medical professionals and family and friends, and chance/luck)
- whether they received support from family and friends, and
- what they believed was their chance of developing the disease again in the future.

What kind of adjuvant chemotherapy treatment did participants receive?

- Participants received a range of different adjuvant chemotherapy regimens, including FEC, AC, CMF and Taxol.
- Most participants underwent six treatment cycles (64%) and the remainder underwent either 8 cycles (30%) or 4 cycles (5.7%).
- Most participants underwent treatment every 21 days (74%) and the remainder underwent treatment every 28 days (15%) or 14 days (11%).
- Most received medication to prevent nausea and vomiting during treatment.
- A very small number of participants received additional medication for other side effects and dose reductions or delays to their chemotherapy treatment.

Did participants experience anxiety?

- The amount of anxiety experienced was moderate and similar to levels of anxiety reported by women undergoing chemotherapy treatment in other research studies.
- Most participants reported experiencing some anxiety symptoms before, during and following chemotherapy treatment.
- The levels of anxiety reported by participants did not change much before, during and following treatment.
- The most common anxiety symptoms reported were the 'feeling of butterflies in the stomach', 'tension' and 'worrying thoughts'.

Did participants experience depression?

- The amount of depression experienced was moderate and similar to levels of depression reported by women undergoing chemotherapy treatment in other research studies.
- Most participants reported experiencing some depression symptoms before, during and following chemotherapy treatment.
- Participants reported more depression symptoms during chemotherapy but less symptoms before and after chemotherapy treatment.
- The most common depression symptoms reported were 'not feeling cheerful', 'feeling slowed down' and 'not enjoying things that used to be enjoyable'.

Did participants experience side effects?

- The side effects included in the questionnaire were fatigue, difficulty sleeping, lack of appetite, pain, sore muscles, nausea, vomiting, dizziness, constipation, memory problems, shortness of breath and coughing.
- Participants reported experiencing many of these side effects during chemotherapy treatment.
- The most common side effects included fatigue, difficulty sleeping, nausea and lack of appetite.

- Participants also reported experiencing some of these symptoms before and after chemotherapy.
- The most common symptoms experienced before chemotherapy were pain, difficulty sleeping, fatigue and sore muscles.
- Participants may have experienced side effects before chemotherapy due to recent breast surgery from which they are still recovering.
- The most common side effects experienced after chemotherapy were fatigue, memory problems, shortness of breath and coughing.
- Participants may have experienced side effects after chemotherapy because they are still recovering from chemotherapy treatment and/or radiation therapy, or may be taking hormone therapy (e.g. Tamoxifen). Coughing may also be experienced after chemotherapy in those participants who smoke.

How did participants cope with chemotherapy treatment?

We looked at a number of ways in which women may cope with chemotherapy treatment. These included:

1. *Information seeking* – refers to the tendency to seek out information about breast cancer and chemotherapy treatment. For example, reading about chemotherapy treatment or talking to others who have undergone chemotherapy treatment in the past.
2. *Information avoidance* – refers to the tendency to avoid or focus attention away from information about breast cancer and chemotherapy treatment. For example, not reading information about chemotherapy or not talking to others about one's experience of chemotherapy.
3. *Emotion-focused coping* – refers to coping efforts aimed at reducing emotional distress experienced during chemotherapy treatment. For example, emotion-focused coping might include talking to friends and family about distressing feelings and thoughts and trying to control emotions.

4. *Task-focused coping* – refers to coping efforts aimed at dealing with challenging issues encountered during chemotherapy treatment. For example, making an extra effort to get chores done before receiving treatment and seeking advice from other knowledgeable people about chemotherapy treatment.
5. *Avoidance coping* – refers to coping efforts aimed at avoiding the distress and challenging issues experienced during chemotherapy. For example, telling oneself that the situation is not happening and taking time off to get away for some time. That is, avoidance coping is more general than information avoidance.

How does coping affect the experience of anxiety, depression and side effects?

- Participants who engaged in information avoidance reported more anxiety, depression and side effects before, during and following chemotherapy treatment than those who did not engage in information avoidance.
- Participants who responded passively to information – neither seeking it out nor avoiding it when it was presented – reported more anxiety and depression before, during and following chemotherapy treatment.
- Participants who used more avoidance coping in general reported more side effects before, during and following chemotherapy treatment.

It is possible that patients who do not seek out information about diagnosis and treatment do not know what to expect from the treatment. They might be shocked or unpleasantly surprised by the treatment, what it involves and how it affects wellbeing and life in general. They might also make few preparations for treatment and its effects. For example, patients who avoid information about the side effects of chemotherapy may be surprised and confused when suddenly experiencing a lot of fatigue. They may be frustrated and ill prepared to deal with the fatigue and the way in which it is preventing them from carrying out their daily activities such as going to work or taking care of their children.

They might not know what to do when they do experience the effects of treatment. For example, patients using avoidance may not know that when their hair falls out, they can obtain a wig from the wig library at Canberra Hospital. Therefore, when their hair does fall out, they might feel distressed and helpless about how they can manage the new change in their appearance.

- Lastly, participants who used more emotion-focused coping reported more anxiety and depression before, during and following treatment.

This finding seems counterintuitive. If someone uses a lot of emotion-focused coping, it might be expected that they would experience less anxiety and depression. It might be that emotion-focused coping is effective in reducing anxiety and depression, but not when it is used too much. That is, patients who engage in a lot of emotion-focused coping might spend too much time focusing on their feelings and therefore experience greater anxiety and depression. Perhaps it would be more effective if less emotion-focused coping was used and more problem-focused coping was used in order to address any of the challenges experienced during treatment that is causing anxiety and depression.

It is also possible that it was participants who were experiencing a lot of anxiety and depression who used emotion-focused coping. That is, they already had greater levels of anxiety and depression and therefore needed to focus more of their coping on addressing these emotions. The research does not distinguish whether the high levels of anxiety and depression occurred first, or the use of a lot of emotion-focused coping occurred first.

What were participants attitudes' regarding the factors that influenced their disease?

Participants were also asked to indicate the extent to which they thought their disease could be influenced by their own behaviours, the behaviours of medical professionals and family and friends, and chance or luck.

- Participants reported that their own behaviour and chance and luck had a moderate influence on their disease while medical professionals and family and friends had a large influence on their disease. This suggests that participants felt confident in the expertise of their doctors and nurses and felt that family and friends provided much needed support.
- The beliefs about what influences their breast cancer remained the same before, during and following chemotherapy treatment. That is, the experience of chemotherapy treatment did not seem to change how much participants believed their disease was controlled by themselves, medical professionals and family and friends, and chance/luck.

Did participants experience support from friends and family?

Participants were asked to report the amount of social support they received from family and friends and how satisfied they were with the social support they received.

- Participants reported that they received a lot of social support before, during and following chemotherapy treatment.
- Participants reported that they were quite to very satisfied with the social support they received before, during and following chemotherapy treatment.
- This reflects the previous finding that family and friends were large influences on participants' disease.

What were participants' perceptions of future risk of recurrence of breast cancer?

Participants were asked to report how at risk they felt they were to a recurrence of breast cancer in the future and how at risk they felt someone else with the same diagnosis and treatment (their peers) were to a recurrence.

- On average, participants felt they and their peers somewhat or moderately at risk of a recurrence.

- Most felt that they and their peers had the same level of risk (74%), with some participants estimating they were less at risk (20%) and a small number of participants estimating they were more at risk than their peers (6%).

How does this affect women diagnosed with early breast cancer in the future?

We hope that the results will have two main outcomes. First, we hope that the research goes some way to detailing the experience of anxiety, depression and side effects experienced by women undergoing chemotherapy treatment for early breast cancer. Few studies have investigated women's experience so intensively. We hope the information regarding the levels of anxiety, depression and side effects can be used to better prepare women for the treatment and to provide health professionals (for example, psychologists) with a better understanding of the experience of their patients.

Second, we also hope that the research goes some way to helping health professionals and patients understand the way in which coping affects wellbeing during and following chemotherapy. By doing so, it may be possible for patients to maximise their wellbeing by employing certain types of coping shown to enhance wellbeing. It is important, however, that more research is conducted to confirm the results of the present study before patients can be encouraged to use certain forms of coping.

Several women commented that the list of coping and side effects included in the questionnaires were not comprehensive enough. We made an effort to use the surveys available for researchers and to keep the questionnaires brief. In so doing, it appears as though we have missed some of the ways of coping that were used and the side effects that were experienced. We hope that future research will address these issues to ensure that women's complete experience of chemotherapy is accurately assessed and understood.

We plan to publish the results of the study in internal academic journals in the coming year. To date, the preliminary results of the research have been presented at conferences in Venice, Italy and Auckland, New Zealand.

Acknowledgements

We would like to thank the many women who so generously and patiently participated in the research. We understand that chemotherapy treatment presents a significant challenge to not only patients but also their family and friends. We are most appreciative of the time and effort spent on participation.

We would also like to thank the many medical professionals, medical oncologists, nursing staff and breast care nurses, for their generous support of the research. Their continual assistance with recruitment was greatly appreciated and vital to the success of the research.

Finally, we would like to thank the ACT Cancer Council who supported the research. We hope the results of the research provide a better understanding of patients' experience of chemotherapy, one of the most challenging medical treatments available. We hope the results provide information of use to health professionals and ensure all women diagnosed with breast cancer in the future receive the best medical and psychological support possible.

Contacts

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