

Research into the Relationship Between Type of Organisation and Effectiveness of Support Groups for People with Cancer and their Carers

Report to The Cancer Council NSW

February 2005

**Professor Jane Ussher¹
Professor Phyllis Butow²
Dr Gerard Wain^{2,3}
Kim Hobbs³
Katharine Smith³
Annie Stenlake³
Dr Laura Kirsten²
Mirjana Sandoval¹**

¹School of Psychology, University of Western Sydney

²Medical Psychology Research Unit, School of Psychology, The University of Sydney

³Department of Gynaecological Oncology, Westmead Hospital

This research was funded by a grant from The Cancer Council NSW

Executive Summary

Executive Summary

The aim of the research project was to examine the nature and effectiveness of support groups for people with cancer in New South Wales (NSW). A statewide audit of existing groups was conducted and an examination of the relationship between type of group and effectiveness was undertaken, using a combination of qualitative and quantitative methods. Further, reasons for people not attending support groups were explored. In addition, a thorough review of the existing research literature on support groups for people with cancer was conducted and national as well as international resources available for cancer support groups were identified. The following research questions were addressed:

1. What is the nature of support groups for people with cancer in NSW?
2. What are the most appropriate methods for evaluating support group effectiveness?
3. How do support groups impact upon quality of life, psychological well being and psychosocial functioning?
4. What is the subjective experience of support group attendance for people with cancer and their carers?
5. What are the organisational, structural and other factors that predict successful group outcomes?
6. Do people with cancer or their carers have a preference for a particular form of support group, and if so, what is it?
7. Why do people with cancer drop out of, or choose not to attend, cancer support groups?

Summary of the Literature

Research has repeatedly identified the pivotal role of social support on the adjustment and psychosocial well-being of people with cancer (Northouse, 1988; Spiegel, Bloom, Kraemer, & Gottheil, 1989). Social support may be provided by family, friends, volunteers, professionals and organisations, yet people with cancer consistently report high levels of unmet need in this area. Social support provided by peers may offer another dimension based upon the commonality of shared experience, which differentiates it from professional interventions.

Best practice cancer care now incorporates published guidelines for the provision of psychosocial support services for patients with breast and colorectal cancer (Australian Institute of Health and Welfare [AIHW] and Australasian Association of Cancer Registries [AACR], 2000). However, comprehensive psychosocial support services are not currently part of routine patient care in most Australian treatment centres. Large numbers of patients and carers, particularly those from rural and remote areas, still do not have access to individual counselling, formal group programs, emotional support or adequate information. The growth of voluntary support groups continues to burgeon, partly in response to the gaps in support services evident in mainstream health care. Whether such groups have the potential to meet the needs of people with cancer, and the mechanism by which they do so, are key questions addressed in this research.

Stage 1: Report on the Audit of Support Groups for People with Cancer and Their Carers in NSW

The study utilised a cross-sectional design and aimed to include all support groups for people with cancer in NSW. Groups were identified through the support groups listings in the Cancer Council of NSW (CCNSW) Services Directory (2001) as well as through the “snowballing technique,” whereby each co-ordinator was asked to name other groups. Support group coordinators were contacted for a telephone interview (see Appendix A) or were mailed a self-report survey (see Appendix B). The interview schedule assessed various aspects of group functioning.

Status of Cancer Support Groups: A total of 223 support groups for people with cancer were identified:

- 178 were active
- 34 had ceased
- 11 were not contactable

Of these, 173 active groups and 11 groups that were no longer operational participated in the study. The majority of the participating groups commenced after 1990.

Location of Cancer Support Groups: Around two thirds of the groups were based in rural settings, one third urban.

Group Leadership: Groups varied in the qualification and cancer experience of the facilitator/s. Over half of the support groups (113, 61%) were facilitated by either one or two health professionals, typically social workers, nurses, psychologists or counsellors. Approximately twenty percent of groups had a person with cancer in a leadership role within the group.

Specificity of Cancer Support Groups: There was a mix of general cancer support groups and groups specific to a particular type of cancer. Within the general groups there were four cultural or language-specific groups. The majority of site-specific cancer support groups were for people with breast or prostate cancer.

Setting of Cancer Support Groups: Cancer support group meetings were most frequently located in either a health care setting (60%) or community (26%) setting.

Aims of Cancer Support Groups: Psychological and emotional support, information/education, and social support were the most frequently identified aims of the groups.

Cancer Support Group Participation: Most groups were open for new participants to join at any time; with between two and seventy-five participants attending the group, and an average attendance of thirteen participants.

Cancer Support Group Structure: The most common frequency of support group meetings was monthly (63%). Over three-quarters of the support groups regularly invited speakers to present at their meetings. Mutual support and sharing occurred in most support groups.

Difficulties with Maintaining Successful Cancer Support Group Functioning: Many groups reported experiencing some difficulties. One challenge for groups was the way in which they dealt with the death of group participants.

Stage 2: An Examination of the Effectiveness of Support Groups for People with Cancer and Their Carers: Part I

Stakeholders' Workshop: A consensus workshop was held to encourage stakeholder and consumer participation in the design of Stage 2 of the project. One outcome of the workshop was a consensus on five key characteristics on which groups varied: 1) *Location* (rural or urban); 2) *Specificity* (people with all cancers included or only those with a specific cancer); 3) *Setting* (group held in health/hospital or community setting); 4) *Leader qualification* (health care professional – e.g. social worker, psychologist, nurse or counsellor, or no health care professional qualification); and 5) *Leader cancer experience* (any person in leadership role with a cancer diagnosis or carer of a person with cancer, or no such experience).

At the workshop it was agreed that the five key outcomes by which support group effectiveness should be assessed should be:

1. *Health related quality of life*
2. *Cancer related empowerment*
3. *Anxiety*
4. *Depression*
5. *Satisfaction with the group*

Following the workshop a stakeholder steering group was formed for further consultation regarding the ongoing research project.

Design of Stage 2: Part I: A prospective study was conducted over one year, in order to examine the effectiveness of different types of support groups for people with cancer and their carers. Fifty support groups varying on key features were selected using a purposive sampling technique. Group participants were invited to complete questionnaires assessing the above five outcomes at baseline, 6 months follow-up, and 12 months follow-up. The first part of the results section for Stage 2: Part I relate to the baseline assessment and as such reports cross-sectional data. The next part of the results compares participants' baseline results to their 6 month and 12 month assessments and as such reports prospective data.

Group participants: The final sample consisted of 47 groups (three refused or had ceased functioning). The final group sample included:

- 17 urban and 30 rural groups;
- 18 general and 29 specific groups;
- 27 groups meeting in a hospital setting and 20 in a community setting;
- 30 led by a health care professional and 17 not;
- 29 with a person with cancer or carer in a leadership role and 18 with no cancer experience in a leader.

Study sample participants: A total of 743 questionnaires were provided to group co-ordinators, and 417 were returned (a 56% response rate), at Stage 1, baseline.

Eighty one percent of participants identified themselves as people with cancer, and 19% were carers. A little over half of the participants with cancer were female, compared to three quarters of carers. The mean age was 64 years in people with cancer and 62 years in carers, which is typical of a cancer patient population. The majority of people with cancer in the sample had breast or prostate cancers. Many people with cancer had been diagnosed more than a year ago and almost half had completed treatment more than one year ago. About three quarters of the sample had early stage cancer when first diagnosed, and identified themselves as without detectable cancer at the time of participation in the study. Treatments undergone were most commonly identified as surgery and radiotherapy.

The five most commonly nominated reasons for joining a support group were:

1. Knowing that I am not alone
2. Hearing about current medical research
3. Becoming more informed about the drugs used in cancer treatment and their side effects
4. Learning about how other people deal with having cancer and comparing my methods for dealing with cancer to theirs
5. Relaxing with others who understand my experience because they are going through the same thing.

The five features of support groups rated by respondents as important or very important were:

1. The group facilitator giving each person who wants to, enough opportunity to talk
2. Welcoming new members and helping them settle in the group
3. Having enough humour in the group
4. The group facilitator's personality
5. The group facilitator understanding how things have been for you.

Results: Baseline

1. **Quality Of Life (QOL) (SF12):** People with cancer reported slightly lower physical QOL than carers, however both groups fell within the normal range as identified in the norms of the SF-12. Interestingly, people with cancer had a significantly higher mental quality of life than carers; 17% of people with cancer and 24% of carers scored significantly lower than standardised population norms on mental QOL.
2. **Cancer-Related Self-Efficacy (CBI-B):** People with cancer reported significantly greater confidence than did carers in their ability to express negative feelings, to maintain a sense of humour, to remain relaxed throughout treatments, to manage their symptoms and side-effects, and to cope with physical changes.
3. **Anxiety and Depression (HADS):** Significantly more carers (21%) than people with cancer (10%) were classified as moderate to severe "cases" of *anxiety*, while approximately equal numbers of people with cancer (6%) and carers (9%) were classified as moderate to "severe" cases of *depression*.
4. **Satisfaction with the support group attended:** The majority of people reported that the groups fulfilled their expectations; about 10-20% reported unmet needs. Needs most likely to be unmet included the opportunity to "give" to others in various ways.

The impact of group factors on outcomes: Associations between *a) group variables* (location, specificity, setting, leader qualification and leader cancer experience) and *b) the outcomes* of anxiety, depression, physical and mental quality of life, self-efficacy and satisfaction, were explored controlling for *demographic variables, disease information and level of social support*.

No associations were found between the group variables and physical quality of life or cancer-related self efficacy. People who attended support groups in a community setting had better mental quality of life, were less depressed, found the group more helpful and were more satisfied with the group's activities than those who attended support groups in a hospital. People who attended a group led by health professionals were more anxious than those attending a group led by non-health professionals. People in general cancer support groups were more satisfied with the activities of their group than those attending groups targeting a specific cancer.

It should be emphasised that the differences between people attending groups held in community versus health care settings and run by health or non-health professionals were small, though statistically significant. Whether the group leader was a health care professional or not, or whether the group leader had had a previous cancer diagnosis or not, was not associated at all with satisfaction with the group leader.

It is not possible to determine whether these group factors *caused* these outcomes. People with cancer attending groups in a hospital setting may have been more anxious before attending a group. A prospective follow-up study over a one year period was conducted to consider the effect of the group over time on psychological outcomes.

Results: 6 and 12 month Follow-up

The 417 individuals who responded to the baseline questionnaire were contacted 6 and 12 months later and asked to complete a follow-up questionnaire. The aim of this follow-up was to examine changes in the relationship between group factors and participant outcomes over time, and to assess the experiences of individuals who dropped out of support groups. The following results report the findings of the 6 and 12 month follow-up. The response rate at the 6 month assessment was 83% (n=345) and at the 12 month assessment was 82% (n=341).

Overall results indicate that in general, mental health, anxiety, depression, and self-efficacy ratings in participants attending cancer support groups improved over time. Where differences between groups were identified in psychological well-being, by time 3 (one year after participants entered the study) those differences were not significant.

1. ***General versus Specific Groups:*** People who attended support groups that were for people with heterogenous cancers had greater improvements in anxiety and satisfaction with the group, than those attending groups for site-specific cancers, particularly in groups that were urban or led by non-health professionals.
2. ***Urban versus Rural Groups:*** Urban groups had better outcomes on several measures. This was particularly seen in carers in these groups.

3. ***Hospital versus Community Setting:*** Mental health status improved slightly in people attending groups in hospitals, but slightly decreased in community groups. Further, whilst levels of depression remained fairly stable amongst people with cancer attending groups in the hospital and community setting, carers attending hospital groups showed a decrease in level of depression over the 12 month period. Apart from these results, group setting did not appear to influence changes over time in psychological and satisfaction outcomes.
4. ***Leadership: Cancer versus No Cancer Experience, Health Professional versus Non-Health Professional:*** There was an improvement in the mental health status of participants in groups led by health professionals, however it was higher overall for those in non-health professionally led groups. Also, mental health status improved in those led by a facilitator with no personal cancer experience, whilst it remained fairly stable in those led by someone with a personal cancer experience. Further, carers in groups led by health professionals showed an improvement in mental health status and depression, however there was a decline in both of these outcomes for carers in groups led by non-health professionals.

Satisfaction with group helpfulness appeared to be higher at the 12 month assessment in people attending a general group with a non-professional leader. Leader characteristics did not appear to be associated with other outcomes, except that participants attending groups led by non-professionals or by someone without a personal experience of cancer, appeared to have more difficulties if the group was not a site-specific cancer support group.

Conclusions: Stage 2: Part I

The results from this study (Baseline and Follow-up) indicate that people with cancer are reporting consistently positive outcomes in the domains of quality of life, anxiety and depression, self-efficacy and satisfaction with their group. The group characteristic associated with the most differences in outcome was the specificity of the group – whether it was heterogeneous or cancer site specific. People attending heterogeneous groups, particularly if led by non-health professionals, appeared to do better, particularly in relation to rapidly falling anxiety levels. Also of importance for outcome was the location of the group (urban or rural), with rural attendees, particularly carers, doing somewhat poorer than their urban counterparts.

Interestingly the differences identified in outcome between the key group characteristics were small and probably not clinically significant. The only exception to this was with regard to level of anxiety in which marked improvement in level of anxiety were noted.

At Baseline significant differences were found between carers and people with cancer on a number of outcomes, with carers reporting lower mental health status and higher levels of anxiety. By the 12 month assessment there were no statistical or clinical differences between people with cancer and carers on psychological outcomes. There was a statistically significant difference between people with cancer and carers on physical health status, however, both groups scored within one standard deviation of the population mean and thus this difference is probably not clinically significant. This observed difference would be expected when comparing a medically ill population with a population that is primarily healthy.

Stage 2: An Examination of the Effectiveness of Support Groups for People with Cancer and Their Carers: Part II

Ten support group coordinators were asked to consent to take part in participant observation and focus group interviews. Nine groups participated in the study. These groups varied in their location (rural/urban), setting (hospital/community), specificity (general cancers/cancer-specific), facilitator qualification (health professional/non-health professional), and facilitator experience with cancer. One of these groups was a non-English speaking cultural group, thus requiring the use of interpreters.

Following the observation of the group meeting, the researchers conducted a focus group interview, using a semi-structured format, to examine the subjective experience of the support group for the participants. The main questions were:

- What do you get out of participating in this cancer support group?
- How does participating in this group interact with your social support network? Is there any way in which you think this group can be improved?

Belonging to a Cancer Support Group: A Surrogate Family

The strongest overarching theme to emerge from the focus group interviews was of belonging to the support group as a surrogate family. Under this main theme, the accounts of the focus group interviews have been divided into four main areas, each with a number of sub-themes as summarised below:

1. Life in the support group family: A sense of belonging.

- A sense of community
- Not alone – metaphorically/literally
- Non-judgemental acceptance
- Empathy/understanding
- Being cared for
- Safe environment for expressing feelings and fears
 - Cancer not a taboo subject/death is not taboo
 - Not having to protect others
- Positive atmosphere – humour
- Challenges within the “family”

2. Benefits of belonging to the support group.

- Pre-group versus post-group changes in self
- Empowerment/agency

3. Functioning within the support group: Modelling, information sharing, and leadership.

- Modelling
- Information sharing: improving communication with health professionals
- The role of the group leader

4. Obstacles to entering the support group: Overcoming negative expectations and finding the right group.

Summary and Conclusions: Stage 2: Part II

The focus group interviews and ethnographic observation with 9 support groups for people with cancer identified the following:

1. Cancer support groups are often positioned and experienced as a surrogate family by participants.
2. This notion of support groups as a surrogate family leads to a strong sense of belonging to a supportive community of empathic others, which counteracts the feelings of isolation experienced by many individuals with cancer.
3. The main characteristics of effective support groups, regardless of type of group, or professional background of the leader are: providing a caring and safe atmosphere for the open discussion of feelings; humour; non-judgemental acceptance; education and information giving.
4. The group leader is an important influence in providing a sense of cohesion, continuity and security in the group, acting as a strong attachment figure, or surrogate parent.
5. Modelling by other group members is also an important factor in group effectiveness.
6. Group members report having experienced a greater sense of empowerment, and an improvement in psychological well being, as a result of attending groups. They report that they are better equipped to cope with cancer, and with other issues in life, because of the support they received in the groups.

The Experience of Non-Attendees and Group Leavers

This phase of the study aimed to explore the subjective experiences of people who choose not to attend support groups and to compare the psychological well-being of support group attendees with both non-attendees and group leavers.

Leavers (i.e., Former Cancer Support Group Attendees)

At 6 month and 12 month follow-up, 87 participants reported having left their cancer support group. Participants who indicated on the returned questionnaire that they were no longer attending the cancer support group were invited to take part in a brief telephone interview.

Comparison of leavers and attendees on demographic and group characteristics.

There were a number of factors which distinguished leavers and attendees. Leavers:

- were more likely to have cancer that was no longer detectable
- were more satisfied in their communications with health professionals
- had spent less time in the group
- were more likely to attend a group that was Sydney based and hospital based
- rated the group leader as less helpful, and were less satisfied with the leader
- were more likely to be in a group with a leader who had a personal experience of cancer

This suggests that a combination of individual and group factors may be associated with individuals leaving: no one factor will predict whether a person with cancer or their carer will leave a group.

Comparison of leavers and attendees on indices of psychological well-being.

Those who had left their group were compared to those who stayed in the group on the HADS. There was no difference in case-ness of anxiety or depression between those who left, those who stayed, and general population figures.

Reasons for leaving the cancer support group.

Reasons provided by those who had left their group included:

- Time to move on
- Have enough support
- Practical issues
- Previous bad experience with groups
- Wanting people “like me”
- Personality/coping style
- Dissatisfaction with group

Non-Attendees (i.e., Individuals who do not Attend a Cancer Support Group)

Twenty nine people with cancer, not attending a cancer support group, were recruited through the outpatient clinics of four oncologists at three Sydney hospitals. Those who agreed to take part in the study were asked to complete a brief questionnaire, and to take part in either an individual or focus group interview. Telephone interviews were conducted with 14 participants, three focus groups were conducted with 15 participants (an average of five participants per group).

Comparison of non-attendees and attendees on indices of psychological well-being.

The HADS scores of those who do not attend a cancer support group were compared to those who remained in a cancer support group during the course of the study. A higher proportion of people who did not attend a cancer support group were identified as definitely anxious compared to those who had remained in a cancer support group. Further, those who did not attend a cancer support group were more likely to be depressed than both attendees and the general population. However, these differences were not statistically significant.

Qualitative interviews.

A number of themes emerged regarding reasons for non-attendance from the qualitative interviews. These included:

- Not wanting to revisit the cancer experience
- Avoiding contact with cancer
- Currently have enough support
- Lack of awareness about groups
- Fearful of exposure/privacy
- Wanting “people like me”
- Personality/coping style
- Does not need psychological support
- Practical issues

Conclusions: The Experience of Non-Attendees and Group Leavers

The qualitative analysis of accounts of people with cancer who do not attend cancer support groups suggests that there are multiple reasons why they do not attend. These reasons can be categorised according to four main factors:

- Positive factors: Do not want to revisit cancer experience; I currently have enough support
- Individual factors: Personality/coping style; Fearful of exposure/privacy
- Avoidant factors: Avoiding contact with cancer; I do not need psychological support
- Group factors: Wanting “people like me”; Practical issues; Lack of awareness about groups

This clearly illustrates the fact that there are many disparate factors underlying cancer support group non-attendance, each of which needs to be taken into consideration when assessing needs for people with cancer and their carers, or when developing interventions.

Overall Conclusions

The results of this research confirm that support groups have a significant role to play in the provision of support for people with cancer and their carers. The study confirms and documents the fact that support groups have a broad range of structures, convene and meet in a diverse array of venues and locations, follow a wide variety of formats, are grouped on the basis of a wide range of characteristics (cancer site, demographic or cultural characteristics), function in many different ways and offer a very large range of support to their participants.

In addition to the literature review conducted on cancer support groups, resources available for cancer support groups were also identified. National and international resources were identified that were either in print form or electronic and the content of these resources outlined. Evident from the resources uncovered was great variability in the detail and descriptiveness of the content. This may reflect the paucity of information available on nature and effectiveness of existing non-therapy cancer support groups and highlight the timeliness of the current study.

Notwithstanding this diversity, the participants express almost unanimous gratitude for the support they obtain from the groups and indicate that they receive unique support from the group that is not obtained elsewhere. In this regard, the study provides strong evidence that the Cancer Council NSW should continue to assist in the delivery of support groups.

The results from this study (Stage 2: Part I: Baseline and Follow-up) indicate that people with cancer are reporting consistently positive outcomes in the domains of quality of life, anxiety and depression, self-efficacy and satisfaction with their group. The group characteristic associated with the most differences in outcome was the specificity of the group – whether it was heterogeneous or cancer site specific. People attending heterogeneous groups, particularly if led by non-health professionals, appeared to do better, particularly in relation to rapidly falling anxiety levels. The location of the group (urban or rural) with rural attendees, particularly carers, doing somewhat poorer than their urban counterparts was also important for outcome.

Interestingly the differences identified in outcome between the key group characteristics were small and probably not clinically significant. The only exception to this was with regard to level of anxiety in which marked improvements in level of anxiety were reported between baseline and follow-up assessments.

At Baseline significant differences were found between carers and people with cancer on a number of outcomes, specifically mental health status and levels of anxiety. In the Follow-up, whilst differences were observed between people with cancer and carers over the three time points, by the 12 month assessment there were no statistical or clinical differences between people with cancer and carers on psychological outcomes. At the 12 month assessment there was a statistically significant difference between people with cancer and carers on physical health status, however, both groups scored within one standard deviation of the population mean and thus this difference is probably not clinically significant. This observed difference would be expected when comparing a medically ill population with a population that is primarily healthy.

Whilst support group non-attendees reported higher levels of anxiety and depression than attendees, this difference was not statistically significant. The research highlights the fact that there many disparate factors underlying cancer support group non-attendance, each of which needs to be taken into consideration when assessing needs for people with cancer and their carers, or when developing interventions.

In considering the results of this study it is important to acknowledge the limitations. These include the self-selection of people into particular groups, which may have affected outcomes; the absence of analysis of occurrences within the groups over the twelve month study period; the focus only on groups that are currently functioning; the absence of information about the specific training needs of group leaders; and the small sample size of non-attendees.

The conclusions of this study were reviewed and endorsed in a workshop setting with a mixture of participants resulting in the formulation of a series of recommendations based on the findings of this study.

Recommendations

The recommendations fall into a number of broad categories, as follows:

Recognition, Networking and Logistic Support For Support Groups: The CCNSW should establish a formal network of support groups; maintain an active register of support groups; explore, in consultation with consumers and support groups, the issue of developing a system to accredit support groups; dedicate infra-structural resources to support groups; and explore the feasibility of funding mobile support group leaders in rural settings to facilitate group development.

Development of Support Group Models and Frameworks: The CCNSW should develop a resource manual for support groups that describes a number of potential organisational templates and addresses alternative methods of providing support either through telephone or Internet services for rural patients.

Specific Needs of Carers: The CCNSW should assess the specific support needs of carers of people with cancer through further research, and through the development of services which meet the particular needs of carers.

Leadership Training and Development: The central role of leadership of the support groups was clearly demonstrated in this study. Further research is needed to explore the personal and professional qualities that make a good leader; to explore the support and training needs of leaders. The CCNSW should subsequently establish a formal program of professional development and support for the leaders of support groups.

Promotion to Health Professionals: The CCNSW should actively promote the role and effectiveness of support groups to consumers and health professionals; should explore current referral patterns and perceived barriers to referrals amongst health professionals so as to increase referral and participation in support groups; should explore opportunities to work with Area Health Services, Area Cancer Services, the NSW Cancer Institute and other relevant stakeholders so as to better integrate cancer support groups into health services; and should promote the appointment of Area Psychosocial Coordinators, to co-ordinate and support local cancer support groups.

Tailoring Support Needs to the Individual: The importance of matching the type of support to the needs of the individual is emphasised, as cancer specific groups may not suit all individuals, or be appropriate for some people at particular times in their cancer journey, or in particular geographical contexts. Alternative needs of support need to be developed and evaluated, with the support needs of those in rural settings being given particular attention.

Access and Information: Attention is needed in regard to access and information about support groups, including the facilitation of wider access to psycho-social support for people with cancer and their carers to overcome practical barriers to support, and the publication of positive experiences of cancer support groups in order to challenge common misperceptions.

Future Research: The CCNSW should further explore the optimal time within the cancer journey at which participation in support groups offers the most benefits. Research into the efficacy of interventions designed to support leaders of support groups should be encouraged as should research into the experience of cancer carers. Further investigation of the efficacy of a range of support services is required to tailor support to the needs of the individual. In addition the CCNSW should explore gaps in the current availability of support groups for specific demographic or site specific groupings.