



**The Sydney Adventist Hospital
Cancer Support Centre**

**Lung and Gynaecological Cancer
Support Groups Project**

Funded by Cancer Australia
Building Cancer Support Networks Grants Program

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EXECUTIVE SUMMARY

The Sydney Adventist Hospital (SAH) Cancer Support Centre (CSC) received funding in 2007 to undertake this project through Cancer Australia's *Building Cancer Support Networks Grants* Program. Project partners were the Cancer Council, NSW and the Australian Lung Foundation. There is a growing body of evidence regarding successful models of cancer support groups, however experience has shown that it is particularly difficult to recruit and retain people in support groups for lung and gynaecological cancers. Accordingly, the focus of the project has been on the particular needs of the two groups and on identifying the key elements of success for their specific support groups.

This report provides an overview of the project under the following headings: Orientation and Research; Key Project Activities; Promotion and Attendance; Qualitative and Quantitative Research; Findings; Recommendations; and Conclusion.

The report details the key project activities utilising the terms of reference to report against the aims of the project. A significant aspect of this project has been the qualitative and quantitative research and these sections were analysed by independent researchers.

The activities of the project have increased awareness of support services, referrals to support groups, and attendance at, the Sydney Adventist Hospital (SAH) support groups for people with lung and gynaecological (gynae) cancers and their carers. The increased awareness and referral to the support services have been achieved through a range of strategies including: collaboration with key health professionals in both the lung and gynae cancer areas; collaboration with cancer agencies; media coverage of key events; direct mail to key health professionals for assistance with referral and promotion of services; website coverage; and circulation of promotional fliers within the community.

The SAH Lung Cancer Support Group is still believed to be the only face to face group in operation in eastern Australia and in spite of nineteen deaths in the past two years, currently has twenty people on the roll. The Gynae Cancer Support Group was established as part of this project and in spite of four deaths has grown from four women at the initial meeting to twenty one on the current roll.

Programs and workshops have been developed to specifically meet the differing needs of each of these cancer groups. These have included: the large Lung and Gynae Forum nights with leading oncologists in the field; a six week experiential program for women with gynae cancers; and numerous smaller participative workshops held within the group meetings. The provision of information has been highlighted as one of the major reasons for attending these support groups so it is seen as essential to continue to provide programs and information workshops specific to the needs of each group.

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The project aimed to refine and evaluate the support group model and the results of both the qualitative and the quantitative research would suggest this model has met the needs of those attending the two groups. The model for the project was the well established SAH CSC, Breast, Prostate and Bowel Support Groups model which has been operating very successfully for many years. The project highlights the need to be flexible in adapting the basic open support group model to suit the needs of each particular group. The need for skilled, well supported facilitators was considered essential. The similarities and differences between the two groups were discussed.

The qualitative and quantitative research demonstrated that, through their attendance at the SAH Gynae and Lung Cancer Support Groups, the participants reported improved quality of life as well as enhanced psychosocial skills to deal with life after a diagnosis of cancer.

In conclusion, the project found that support groups fulfil a very real need for people with lung and gynaecological cancers particularly those with advanced disease and a subsequent poor prognosis. This project has shown that attendance at a support group can improve the quality of life for both the person with cancer and their partner or carer.

The major outcomes for participants, regardless of whether lung or gynae cancer patient, male or female, patient or carer, were – a feeling of not being alone; access to quality information; the support of others who are understanding, compassionate and caring; a safe environment where feelings can be fully discussed; and a strong sense of family or community.

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BACKGROUND

The Sydney Adventist Hospital (SAH) Cancer Support Centre (CSC) received funding in 2007 to undertake this project through Cancer Australia's *Building Cancer Support Networks Grants* program. Project partners were the Cancer Council NSW (CCNSW) and the Australian Lung Foundation (ALF). There is a growing body of research regarding successful models of cancer support groups; however, experience has shown that it is particularly difficult to recruit to and retain people in support groups for lung and gynaecological cancers. With no significant early symptoms and a lack of early diagnostic tools for these cancers, they are often diagnosed in an advanced state and with poor prognoses. They are perceived as underfunded and tending to receive less attention either from a medical research perspective or on a psychosocial basis. Yet these two groups have such significant needs and we are aware that the provision of adequate support and appropriate information play such an essential part in facilitating adjustment and a sense of control with a diagnosis of cancer.ⁱ Accordingly, the focus of the project has been on the particular needs of the two groups and on identifying the key elements of success for their specific support groups. It was not intended to gather information that replicates existing research findings, but rather to add value to the existing research.

AIM

The aim of the project was multifaceted:

1. To increase awareness of support services, referrals to support groups, and attendance at Sydney Adventist Hospital (SAH) support groups for people with lung and gynaecological (gynae) cancers and their carers.
2. To develop, monitor and evaluate specific programs to meet the future needs of those with lung and gynae cancers and their carers.
3. To refine and evaluate the support group model, making it available to other interested parties
4. Through their attendance at these SAH support groups, to facilitate improvement in attendees' perceived quality of life as well as their psychosocial skills to deal with life after a diagnosis of cancer.

The Working Party and the newly appointed project coordinator developed the terms of reference against which the project could be measured. These were as follows:

- | | |
|-------|---|
| TOR 1 | Provide information about the key project activities, participants, implementation, expenditure and resources. |
| TOR 2 | Determine the extent of increase in referrals from Health Professionals for patients with lung and/or gynaecological cancers and identify key influencing factors. |
| TOR 3 | Map referrals from alternative sources [ie, other than from HPs], record any increases over time, and where possible, identify links to promotional or other activities undertaken through the project. |
| TOR 4 | Identify the extent to which initial referrals lead to people joining a support group, and the factors that influence such decisions. |
| TOR 5 | Identify any increase in the numbers of people joining support groups and/or attending education services over time, for each of the two cancer types. |

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- TOR 6 Determine the extent to which people who join a support group continue on as a member [i.e. beyond one or two meetings], and what factors influence this?
- TOR 7 Identify improvements in quality of life for support group participants.
- TOR 8 Document any key success factors which are considered unique to support groups specifically for people with lung and/or gynaecological cancers [i.e when compared to the existing research]

REPORTING OUTLINE

To facilitate the incorporation of the eight TORs, the project will be reported as follows:

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|----|--|----------------------|
| 1. | KEY PROJECT ACTIVITIES | TOR 1 |
| 2. | PROMOTION AND ATTENDANCE | TOR 2,3,4,5,6 |
| 3. | QUANTITATIVE AND QUALITATIVE RESEARCH | TOR 7 |
| 4. | FINDINGS | TOR 8 |
| 5. | RECOMMENDATIONS | |
| 6. | FINANCIAL STATEMENT | |
| 7. | CONCLUSION | |
| | EXECUTIVE SUMMARY | |

ORIENTATION AND THE PRELIMINARIES

Preliminary activities for the project co-ordinator included:

- Orientation and working with relevant health professionals within the Sydney Adventist Hospital.
- Networking to build collaborative relationships with doctors and key health professionals involved in psychosocial cancer care, at; Westmead Hospital; Royal North Shore Hospital; North Shore Private; Royal Prince Alfred Hospital; the Mater Hospital and the Royal Women's Hospital.
- Interviewing health professionals regarding their observations of the needs and concerns of cancer patients (and their carers), in relation to support and information.
- Developing qualitative research requirements and obtaining ethics approval
- Conducting one to one interviews with a sample of current support group attendees to establish perceived support and information needs.
- Designing a system to capture required data: initial client contact with CSC, face to face, by phone or email; ongoing telephone, email or in person communications by group facilitators; support group attendance; attendance rates for all activities for the two groups.
- Designing a support program based on information collected from initial interviews.
- Designing fliers to promote both gynae and lung programs which were circulated widely through public and private hospitals, medical practices, cancer support services, media and community venues.

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1. KEY PROJECT ACTIVITIES

1.1 Gynaecological (gynae) cancer support activities

The Gynae Cancer Support Group. Toward the end of 2007, the Project Co-ordinator was contacted by several younger women with gynae cancers expressing a need for meeting with other younger women. Their rationale was primarily they wanted to meet with other women in similar circumstances – young married mothers, experiencing early menopause and perhaps sexuality issues while juggling employment, family needs and treatment. Thus the SAH Gynae Support Group was established according to the successful SAH model already operating for bowel, breast and prostate cancers. The first meeting was held in August 2007 with four women in attendance. The women elected to meet monthly and to then review their needs following the six week experiential program. Women unable to attend were intermittently contacted by phone and email.

Gynae Cancer Program After extensive consultation with the women concerned, an experiential program was developed, promoted and implemented. It operated weekly over six weeks commencing on May 27, 2008. The program provided current information on a range of informative topics to assist women in their cancer journeys.

SAH Gynae Cancer Support Group Experiential Program (Table 1)

1.	<i>All you want to know about Gynae cancers. Your questions answered.</i>	Gynaecologic Oncologists
2.	<i>Relationships, Communication & Intimacy</i>	Sexual health and relationships counsellor
3.	<i>Eating and Exercising well</i>	Qi Gong & integrative medicine researcher, University of Sydney Nutritionist, Cancer Council NSW
4.	<i>Mindfulness Meditation</i>	Clinical psychologist, Sydney Cancer Centre
5.	<i>Facing Death, Embracing Life: Living with Uncertainty</i>	Counsellor, Spiritual Care Educator
6.	<i>Your Life Stories, Writing as Healing</i>	Director, Storyworks Australia

Both process and impact evaluation were very positive as was the verbal feedback at the next meeting. One of the positive outcomes of the program was the high level of interest in attending a regular support group for the majority of program participants.

This interest stimulated a good deal of discussion as the newly formed group had been established for younger women but the SAH had no specific group for the older women with gynae cancers who had historically attended a general support group at the centre. As a consequence, members of the original group were canvassed for their opinions regarding opening the group up to the broader age range. It was suggested that there would be a pilot period of three months after which the new model would be evaluated to ensure each group's needs were met.

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By December it was evident that the larger group had been a success and members were canvassed once again regarding their needs in: frequency of meetings; style of meetings; speakers and topics; and any other requested activities. Having tried fortnightly meetings, the group decided they preferred to meet monthly, two hour Monday morning meetings with a speaker at about two out of three meetings. Contact details were exchanged with a view to maintaining contact between meetings. Invited speakers to date have included:

- CNC Gynaecological Oncology, Royal Prince Alfred Hospital, Q & A sessions, three times. The CNC assisted the project coordinator in establishing the group and has kindly agreed to attend two or three meetings per year.
- Registered Nurse & Naturopath, Nutrition & Healthy Lifestyle while living with cancer.
- Psychologist, Resilience & Coping with Loss (after first death in the group).
- Cancer Voices, Advocacy
- GO Fund, Royal Women's Hospital, fundraising for an early detection tool for ovarian cancer.
- Psychologist, mindfulness meditation

All sessions evaluated very well.

The group currently has a roll of twenty members who receive information and regular email communication regarding meetings and speakers. Attendance generally ranges between eight and fourteen women with higher attendances for speakers sessions. Although the SAH is over twenty five kilometres one way for at least five participants, many of the regular attendees make the journey and often have lunch together afterwards. There is a very high level of supportive email and SMS communication between a small core of original members. The group is facilitated by the Project Coordinator who has a strong background in women's health and counselling. She is currently assisted by a volunteer facilitator with a psychology background. No partners or carers have attended this group and the focus tends to be more about support and sharing experiences and stories, while guest speakers provide specific information. While four women ever listed with the group have died, only one was a regular attendee and a foundation member. Twenty five women have ever attended this group.

The only other known gynae support group currently operating in the greater metropolitan Sydney area is the very successful long running group at Westmead Hospital. Westmead has a well resourced gynae oncology unit where regular multi disciplinary meetings are the norm and all patients are seen by a psychologist and/or a social worker who encourages them to attend some meetings. This multidisciplinary model of encouraging women to attend support services has been shown to be highly successful but is unfortunately unavailable for most women in NSW.

Well publicised forums or specific programs have proved to be effective recruitment tools and means of informing people, not only about the cancer journey but about the many facilities available at the SAH Cancer Support Centre. Consequently, a Gynae Cancer Forum, *Gynae Cancer in 2009, Current Treatments and Research* has been arranged for June 18, 2009. Two women with gynae cancer will share their experiences. The promotion of the forum has used the database compiled for the 2008 Gynae Program. A large mailout and email notification has been effected as well as the placement of the attractive posters around the hospitals. Local media coverage has also been arranged.

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The group had constantly shown an interest in advocacy and the desire to inform other women about gynae cancers. This interest then progressed to a suggestion to link up with an organisation fundraising for research into an early diagnostic tool for ovarian cancer. A partnership was forged with GO Fund (a joint initiative of the Royal Women's Hospital and the Garven Institute) and a "Night with Frankie and Jean", hosted by *The San* Gynae Group on June 27, 2009, has been arranged with all tickets sold six weeks prior to the event.

1.2 Lung Cancer Support Activities

Lung Cancer Support Group. At the time of the commencement of the project, the SAH had the only face to face Lung Cancer Support Group operating in NSW (CCNSW operates a lung cancer telephone support group). The group had commenced in 2004 and at that stage had three patients on the roll. The group has continued to meet fortnightly, facilitated by a skilled volunteer facilitator with a strong scientific background and a sound knowledge base of the disease. Often the majority of the cancer patients are in an advanced stage of the disease and thus undergoing regular chemotherapy, the predominant need of the group is for information. However, it has become a very close knit and resilient group needing to continually sustain itself through regular set backs and deaths of its members.

Most of the group attend with partners or carers and during some sessions the group divides so that both the patients and the carers have their own discrete time discussing their own concerns and challenges. This practice is welcomed by both groups as will be seen in the qualitative research results.

A Lung Cancer Forum was held in 2007 with some success and the evaluation results assisted in a highly successful Lung Cancer Forum being held in October 2008. A respiratory physician and chairman of the Global Lung Cancer Coalition and a medical oncologist from RNSH, spoke on "*Lung Cancer in 2008 and Current Treatments*", two cancer patients and one carer then told their stories prior to the forum for questions and answer. 42 people attended and the evening evaluated very positively and a report was completed.

Partly perhaps due to the declining health of several members, the group had also requested a workshop on *Embracing Life and Facing Death*. This workshop was held in September, 2008, facilitated by the Centre Manager and evaluated very well. As the disease continued to progress for several members and there were concerns for some carers it was decided to hold separate interactive *Resilience* workshops for both groups, patients and carers. The workshops, held in January 2009, facilitated by psychologists really met the needs of both groups and evaluated very well.

Five members of the group died in 2007, eleven in 2008 and three so far in 2009 demonstrating the extreme challenges in operating a Lung Cancer Support Group. The impact of this numbers of deaths is highly significant for all members of the group and will be further discussed in the research results. At present there are twenty two listed members of the group. Fifty two people with lung cancer have ever attended this group accompanied by an almost equal number of partners or carers.

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1.3 General Activities

A very successful generic workshop, *What Else Can Help?* was held at the CSC in February 2009, with topics including: Exercise & Qi Gong; Healthy Nutrition; Mindfulness Meditation; and Writing as therapy. Twenty four people attended the workshop and the evaluations were very positive.

Participants in both groups have increasingly utilised the facilities and courses available at the CSC. These include: a well stocked library with books, CDs and DVDs; free reflexology, massage and counselling; ongoing qi gong, choir, music appreciation, storytelling, meditation, Christian meditation; as well as specialist speakers on a range of requested topics. The group members anecdotally state how much they appreciate the services available at the centre and that they appreciate having the link with a respected acute care hospital

2. PROMOTION AND ATTENDANCE

2.1 Networking and the Extent of Health Professional Referral Increase

The new project coordinator who took over in April 2008 continued to network vigorously with key personnel at the various hospitals, both public and private. All SAH support group activities were widely promoted, for major activities this included email notification as well as a wide circulation of colourful promotional fliers. For major events, local media coverage was arranged. Every opportunity was taken to engage with oncologists in particular on how best to encourage their colleagues to inform all their patients about psychosocial support activities, and to discuss potential barriers. Anecdotally, most stated it was the time factor, being focussed on their specific clinical information and one senior oncologist said he believed ignorance was a factor. In elaborating he stated that support groups come and go and he found it difficult to remember what relevant groups were in operation.

Anecdotally, we have been informed there has been a growing awareness and recognition of the two SAH groups by health professionals. This has been as a result of: networking by the project coordinator; constant communication by mail and email of new initiatives and programs; communication with peak bodies and invitations to visit the CSC; invitations to oncologists to speak at forums and workshops thus meeting the specific group and seeing first hand how the CSC functions; recommendations and feedback from their patients of the benefits of the groups; and circulation of evaluation of programs.

The issue of how members of the public perceive support groups perhaps remains a critical factor as one Clinical Nurse Consultant (Gynae Oncology) said she strongly encourages all women to attend a support group (to see whether it suits them) but very few do. Certainly, we are constantly informed that our promotional fliers are well displayed at all the hospitals listed. It is very evident that more needs to be done to develop an appropriate tool to facilitate easier referral for all health professionals. It is known that encouragement by a respected health professional is a strong motivator to act.

The project coordinator also visited the Peter MacCallum Cancer Centre and the BreaCan Support Centre in Melbourne to discuss models of support, what works, what doesn't and to hear recommendations. Regular contact has also been maintained with Ovarian Cancer Australia who have recently established an Ovarian Cancer Support Group in inner Sydney. The Project Coordinator and seven Gynae Group members attended an Ovarian Cancer Awareness breakfast hosted by Ovarian Cancer Australia in February 2009.

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2.2 How People Heard!

The following table 3, “How people in the groups heard about The SAH CSC support groups” is from the February 2009 project questionnaire and demonstrates a broad range of referral sources:

Word of mouth	9	
Oncologist	1	
Other health professional	3	
Internet	2	
Cancer Council	2	
Attended a program at the San	7	
Other	5	(included seeing flier at place of treatment)
Multiple	3	

It should be noted that twenty seven people completed this questionnaire and some of these ticked more than one field. Thus, having heard in a variety of ways, new members continue to arrive having heard about the support groups. Since January 2008, ten new women have joined the gynae group and fourteen patients (most with carers) have joined the lung group. While it is evident a number of strategies are effective to some degree, health professionals at the other hospitals believe there has been a groundswell of recognition for the activities of the two groups and for the facilities available at The SAH CSC. Word of mouth was a strong strategy for the women who informed other women they met at activities such as *Look Good Feel Better* or the Greater Metropolitan Clinical Taskforce (GMCT) Gynaecological Oncology, Weekend Retreats.

It is evident that running specific cancer programs (ie Lung Forum or Gynae Forums) provide a non threatening opportunity for people to visit the CSC and discover the services available. A significant number of these people then join a support group. It should be noted however that the forums or educational activities are reliant on careful planning, energetic promotion, and on engaging excellent speakers (both in terms of latest information and research but also ensuring the speakers are very approachable and eager to answer all questions). Evaluation then assists in demonstrating what was valued and what might be modified for future events.

2.3 Rationale for Attendance/Non Attendance

As will be seen in Section 3, members of both groups attend whenever they can and find the meetings a positive experience. Six women on the Gynae Group roll, like to receive information about the group although they are not coming to meetings as they state: they are in remission at present and “getting on with life”; the SAH is too far away but “good to know you are there”; or time issues such as the pressure of juggling little children, job and home.

Of the small numbers with either lung or a gynae cancer, who have attended programs or visited the centre and elected not to join a support group their responses are similar to those who stay on the roll to receive information but elect to not attend meetings, ie, earlier stage of the disease, sufficient support, distance from the SAH, and competing time issues. Conversely it should be noted that for many regular attenders to both the gynae and lung cancers groups, the disease is already advanced so these patients and their partners/carers are often particularly anxious and wanting to “leave no stone unturned” to learn more.

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They greatly value talking with others “in the same boat” and the opportunity to access to more information about their cancer and treatments. Thus they appear to be more likely to want to attend regular support meetings than those diagnosed with cancer in the non invasive stage.

2.4 Positive Outcomes for the SAH Cancer Support Centre

The SAH CSC is a well established and respected centre already offering a wide variety of services to people diagnosed with cancer and their families. However, one of the secondary reasons to apply for the project was to provide the SAH CSC with specific information to assist in enhancing its’ reputation as a centre of excellence in cancer care through the development of a ‘best practice model’ or perhaps variations of this (see Section 4). Through developing a database and with the activities of the project, the centre has been able to measure the increases in contacts with the centre, attendances and the breadth of volunteer facilitator activities. Besides an increase in the use of all services and the building of both lung and gynae cancer groups, other positive spin offs from the project have been: an increased database of excellent speakers (ie nutrition, resilience, qi gong, mindfulness meditation, writing as therapy etc); collaborative relationships with many oncologists and peak bodies. One such example is the Australian Lung Foundation, one of the project partners. Through this liaison, a lung physician has attended the SAH Lung Group on several occasions, has spoken at a Lung Forum, had the CSC Manager invited to speak at the Australian Lung Cancer Conference in 2008 and assisted a lung cancer survivor in fundraising for lung cancer research. He has also invited the Lung Group coordinators to a multidisciplinary meeting at Concord Hospital essentially to highlight to the multidisciplinary team, the referral process and the very positive aspects of the group and how it operates.

Through the work on the project at the Sydney Adventist Hospital, the project coordinator is currently under consideration for a Churchill Fellowship to build on the work to date. If successful, the aim of the Churchill Fellowship would be to examine “best practice” models of psychosocial support for women with gynae cancers in Northern America and the United Kingdom, as well as exploring an effective electronic referral tool for oncologists and other health professionals.

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3. QUALITATIVE AND QUANTITATIVE RESULTS, QUALITY OF LIFE

The working assumption is that being diagnosed and living with a gynae or lung cancer can bring experiences of confusion, disbelief, anger, sadness and isolation. It is believed that bringing together people with a specific cancer in a support group can alleviate the sense of isolation, help make sense of the situation and contribute to an improved sense of wellbeing. Thus to add to the current evidence of the potential benefits of psycho/social/spiritual support from these two groups, qualitative research was carried out. There has been increasing interest in the role of qualitative research in the area of cancer support with the evidence that it provides “a more indepth and nuanced examination of the experience and consequences of attending cancer support groups”.ⁱⁱ

A survey was designed, tested and ethics approval obtained. Participants were informed that taking part in the interviews was entirely voluntary and information provided would be confidential. Participants were required to sign a consent form. The questions fell into two categories

1. Questions about support groups themselves and their involvement in them
2. Questions about well being. Enquiries about whether involvement in the support groups or the support program generally had any influence on any aspects of well being, including:
 - levels of calm or anxiety
 - contentment with the quality of relationships
 - levels of physical wellness or unwellness
 - contentment with life as a whole

The interview data obtained in this study was analysed by an independent research psychologist using the principles of Interpretive Phenomenological Analysis [IPA]ⁱⁱⁱ in this method of analysis, the perceptions of the participant on the particular subject matter are explored. As the analysis is not concerned with the objective statement of the subject matter but instead endeavours to extract the participant’s perception of the event, it is considered phenomenological^{iv} (Smith, 1999; Smith & Osborn, 2003). Through the assumption that there is a connection between the individual’s verbal report, cognition and physical state, IPA explores the verbal reports of the individual in order to extract the underlying cognitions. The researcher carefully read the transcripts and the main themes were extracted. A coding frame was developed and transcripts were then coded line by line according to content (descriptive category) and theme (interpretation or meaning) using NVivo 8 computer package. Themes were then checked for emerging patterns, for variability and consistency, for commonality across participants, and for the function and effects of specific accounts.

In addition to the qualitative interviews, members of both groups were asked to complete a questionnaire in February 2009. Eleven members of the gynae cancer group, eight lung cancer patients and eight lung cancer carers completed the questionnaire and these were in turn analysed by an independent researcher. Caution needs to be taken in the interpretation of results due to the small sample sizes. The researcher also pointed out that due to the project coordinator being the interviewer for the research as well as having a role in the facilitation of both groups, there may have been limited discussion regarding the importance of the group leader for either group. From her previous research, she stated “I am certain that if this were not the case, there would have been more emphasis and discussion about how highly valued group leaders were.”^v Some positive comments about the role of the leaders were made in the quantitative section and these were also highlighted in the annual evaluation for both groups.

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With the questionnaire results, caution needs to be taken in interpreting the significance testing, for both the two-way between-groups analysis of variance and chi-square tests. With a small sample (less than 30), it is possible that non-significant results may be due to insufficient power. As a chi-square assumption was violated (cells with <5 in the expected frequency), the Fisher's Exact Probability Test was used. Additionally, due to the small sample size involved, the alpha level was adjusted to $p < .10$ to compensate.

Due to the differences in the groups they will be reported on separately. The gynae group is of course, all women, does not include carers, has a considerably younger mean age, and a slightly higher education level. Their group meets monthly, is presented in a more support focused model with invited speakers to provide in depth information on a range of topics. In comparison, members of the lung group and the lung cancer carers were slightly older, mainly retired and of mixed gender. This group meets fortnightly with a more information focused model and a highly informed facilitator. Where appropriate, these results will be reported in context with the results of the interviews and a combined analysis will be at the end of this section.

3.1 Gynae Cancer Participants

There were five gynaecological cancer patients interviewed. One patient was interviewed once and the remainder were interviewed twice. A total of nine interviews were included in the analysis.

Participants ranged in age from 43 to 61 years with the mean being 49.8 years. Four participants were married and one was divorced. Participants had all attained a college or university level education.

Four participants had children. All participants had advanced or recurrent disease with one participant dying in late 2008.

A number of themes were identified from the interviews, which are presented in the results section below (see Table 4)

Main themes
1) Reduced isolation
2) Compare self to others
3) Understanding & acceptance
4) Sense of belonging
5) No need to protect others
6) Family & friends
7) Information
8) Opportunity to give back
9) Negative aspects of attending
10) Humour

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1) **Reduced isolation** was highlighted as an important reason for joining the gynae group as it provided an opportunity to meet similar others. This was highlighted again in the questionnaire when several women reiterated the value of meeting others “in the same boat”, “knowing I am not alone and sharing similar experiences.” When discussing the reason for attending the group, the timing of joining the group was important. Participants said they joined when they were ready to attend the group or looking for some sort of support. This was often after all initial treatment was completed. One woman stated:

During the treatment, the chemo and things, I'd spend a lot of time alone and feeling quite isolated,

While another said: I guess it's that sense that you're not the only one going through this sort of thing.

Whilst people could identify with others because they first, had cancer, and second, it was a gynaecological cancer, there was also appreciation for attending a group with people of a similar age. One person commented on the fact that the women with whom she went through treatment were much older. In the questionnaire, one participant explained how the change in the group to include all ages changed her group experience. It was important for her to be with people of the same age or developmental / life stage. For some women this was less relevant.

2. **Comparing self to others** was considered helpful as it provided participants with an opportunity to see others further along the cancer journey. For the most part, the effect of seeing others and comparing their own situation to other members had a positive effect on participants.

Probably even before I got the recurrence, meeting somebody else who had a recurrence ... it's that sense that this happens. Somebody who was dealing with similar things that I then dealt with.

You're hearing about people's experience, I suppose in my case it did show me how very fortunate I am

3. Respect for differences highlighted the importance of **understanding & acceptance** within the group. In general, amongst participants there was great appreciation of having a forum to meet with others, no matter how similar or how different. As a result of these interactions, participants reported viewing their own situation in a different light, for example, “I felt more appreciative of my relationship with my husband and probably my friends too.” I also recognized that people are different and respected and accepted those differences within the group.

It's interesting too in that there is no 'right' or 'wrong' way to cope; everybody copes differently

4. This feeling of being understood appeared to allow a certain level of depth and honesty that perhaps participants did not necessarily experience in all their relationships outside of the group. This understanding and acceptance within the group contributed to a **sense of belonging** and a couple of women likened the experience to that of belonging to a club.

I feel like I'm part of a club and I really like the club which is a funny thing to say about having a life threatening illness but I like being a part of the club ... because no body knows what it is like to have a life threatening illness unless you've got one.

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Responses to the questionnaire included:

- *[the facilitator] and the group are an amazing and inspiring group of women whom I feel, despite the circumstances, that I am privileged to have met.*
- *[belonging to the group] helps give me encouragement, positive thoughts and hope as well*

5. Within the group there was **no need to protect the feelings of others**. In this way, participants reported that they could express their fears without feeling that they might upset people around them; they could discuss topics that they would not talk to other people about, such as sex and death.

In our core group, you just cut to the chase, you just know each other and you know each other's intimate sex lives and everything in an instant. There's no holding back.

In fact, there was a sense for some that the group was the only place where they could express those concerns and what that means to them.

I'm finding like nobody will acknowledge to my face how serious this is. There is a lot of beating around the bush. Maybe they actually know but it's a sort of 'you'll be alright', a positive thing and I say 'well actually I won't be all right; it's a matter of time. I'm fine now but we'll see ... this is a terminal illness.' ... they don't want to know so that's where the support group comes in. People there actually understand - you don't have to go through all that!

6. Several issues were raised in relation to discussing aspects of their situation with **family and friends**. On one level, in discussing and appreciating difference between group members, it also highlighted to one member how difficult it can be for family and friends to know how to help. As a result, belonging to the group affected communication with her family and friends. One woman described how the death of a group member provided an opportunity for her to discuss such matters with her family

7. Apart from the emotional support, participants identified **information** as an important outcome of group membership. The information sharing in the group occurred at a number of different levels and included several topics: information about the cancers themselves; current research; treatments and side effects; and what else helps. One level of information was from invited speaker to member.

[The speakers] have been fantastic, really very high quality ... because there is so much information around of variable quality ... and it gets to be a bit of a maze, bit hard to know what to believe ... so it's quite reassuring when you know that you've got really, really top people in their field and okay, so these are the top people, so you're going to believe someone. This is what I'm going to eat because this is what they suggest!

Another level was from facilitator to member with the facilitator being perceived as a person who would always go and find the right speaker for the group, find information or source a new internet site. Another important source of information in the gynaecological cancer support group appeared to be from member to member

I think we help each other out with our understanding of the disease ... so I think it does help in that way. Like [group member A] has educated us a lot in what she's found out about the

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cancer.... and she had to be that way because her diagnosis was so late but I was basically unaware of so many things so it's helped in the education process

8. Interestingly several participants valued the **opportunity to give back** to others inside or outside the group.

I think I've been given an opportunity to spend more time with a group of women and I've had more time to devote to getting to know them better and so that affects the way I deal with other people in my life that I can see how giving more gives you more in return and so I'm probably a different person on that level too outside the group.

9. There were several individual preferences stated in terms of **negative aspects of attending** the group. One participant liked a small group another a larger size group. One woman found the repetitious questioning frustrating while another spoke of the need for more in depth sessions. One woman was able to articulate that, because of the openness and acceptance of the group facilitator, there was a sense that the group could go in the direction that members saw fit.

I think our gynae group is really good because it's flexible. I feel [the group facilitator], is very approachable for example, nothing has ever struck my mind like "Oh, I wish we had this" because if something crosses your mind ... it's open to be able to say "Oh, that would be interesting" [lets suggest that!]

As would be anticipated there was the challenge of hearing when someone has bad news.

When you lose a member of the support group through the ravages of the disease, it makes it very difficult on the other members. The death is no longer another statistic It is the passing of someone you knew and it brings home the difficulty of one's situation.

In terms of improving the group, one participant suggested that the group takes more of a role in advocating for people with gynaecological cancers.

10. Despite the negatives of attending the group, there was recognition that the **humour** in the group was very important.

I feel that despite all of the stuff that we are going through ... we can still laugh and we can still joke about our circumstances. I think that is just so important to still accept it for what it is because there is nothing we can do to change it so part of a [support] group for me is being able to accept that it is what it is and we can laugh about it and joke about it.

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3.2 Lung Cancer Participants

There were six lung patients interviewed. One patient was interviewed on one occasion, two were interviewed twice, and three were interviewed three times. Six carers of people with lung cancer were interviewed; four were carers of patient participants. Of the lung patients, five were female and one was male, whilst for the carers there were two females and four males. Only one participant was divorced with the remaining 11 being married, eight participants forming four married couples within the study. By the end of the data collection in March 2009, three of the lung patient participants had died and four of the lung carers were bereaved, two of the four married couples participating in the interviews included a bereaved carer. Participants were all over 50 years and mostly retired. Participants were mostly Caucasian.

A number of themes were identified from the interviews, which are presented in the results section below (see Table 5)

Main Themes
1) Initial negative impressions of support groups
2) Information
3) Not alone
4) Compare self to others
5) Commitment to the group
6) Caring
7) Acceptance and understanding
8) The role of the group leader
9) Humour
10) Carers
11) Family & friends
12) Influences on communication with health professionals
13) Giving back to the group
14) Challenging experiences within the group
15) Sense of empowerment

1. Some participants described **initial negative impressions of cancer support groups** and thus being reluctant to attend a support group. Reasons for this included concern about being identified as a cancer patient, being around 'sick' people or discouragement by family members. Conversely one participant was encouraged to attend by a family member. Irrespective of how people eventually attended the group, and despite the initial reservations, participants said that they really "look forward to going" to their group.

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2. **Sourcing information** was of great importance within the lung cancer support group. The information suppliers were health professionals/guest speakers, the group leader and the members themselves. The information provided at all levels was considered valuable.

The group has been a great support group for both of us in terms of being able to gain information in terms of our plight with lung cancer, with the people present, certainly from [the group leader]... then of course you have the actual participants themselves ... each on a different path or journey, each trying different treatments so that you gain access to current, and past treatments that have been successful and it gives you other information that you can direct back to your doctor to question whether or not this is the path you should be following. So in some sense it acts as a check list that you are asking the right questions of your doctor

3. A valuable aspect of belonging to the group was knowing “**you’re not alone.**” This was important for both patients and carers.

You can share with people who are knowledgeable and people who have experienced it. It really is what they say ‘a burden shared, is a burden halved’ ... because when you feel isolated it’s a very lonely sort of feeling, but when you’ve got others its not.

One bereaved carer said: *I think it would have been hell on earth to do it on your own, without the knowledge that others are in the same boat.*

4. Every participant interviewed identified that the group provided them an opportunity to be with others who were going through the same thing and gave them an opportunity to **compare self to others**. This was important for newly diagnosed.

We came fairly soon after diagnosis, within 2 or 3 weeks when I think we were in a terrible state and just to hear people say ‘this is my 10th year. It helped us to sort of calm down a bit and get our feet on the ground

The points on which people compare themselves to others are not only in terms of physical well being but also emotional well being. They commented on how much they learned from how other group members handled certain situations. One person spoke of having “derived strength and inspiration from others resilience and positive attitude”. Sometimes the comparisons were positive, for example, seeing someone who has survived for 10 years or have been through a similar therapy and are doing well. Sometimes these comparisons were based on seeing someone worse off themselves that seemed to elicit a sense of feeling lucky or of being ‘better off.’ However one participant commented on negative comparisons such as envy when someone had finished chemo when she was just starting or perhaps feeling envious of another participant’s level of family support.

5. There was a strong expression of **commitment to the group**, not only in terms of not wanting to miss a meeting themselves. A couple of participants stated they didn’t like to miss a meeting because they didn’t want to “let the group down”.

6. The commitment to the group appeared to reflect **caring** about the well being of other members in the group.

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I'm a quiet person but coming here I find you are more open to asking questions and it makes you more interested in other people's problems and not just your own. Makes you a more caring person.

[Initially attending the group] was propelled by your own needs. As we go further into and get to know the group, you realise that it's caring about other peoples' needs as well; their trials are yours and disappointments are yours as well.

7. Interestingly, there was a “**sense of community**” within the group with some participants making the comparison of the group to being like a family, despite, not unlike a family, the diversity within.

8. Regardless of the differences in the group there was **acceptance and understanding** amongst members such that each person's choice was their own.

People support that – that people are taking the path they want. They offer advice, but no one's upset if it isn't taken

9. Participants valued many aspects of the group. One was **the role of the group leader** who was seen as an important source of information and also valued for leadership skills especially in executive functions, such as providing structure for the group. One questionnaire response was:

It is most important to have the right co coordinator to run the meetings. They must show ... understanding, compassion and caring ... to be able to bond and be able to help with the cancer patients. [The group leader] has all of these and more

10. Participants also valued the **humour** in the group which some had not expected.

11. They also valued the fact that **carers** were made to feel very welcome at the lung group meetings. Some participants, both patients and carers, mentioned appreciation for the times when the group did separate into patients and carers for part of the meeting. The influence of the group went beyond providing emotional support to patients and carers and in fact impacted on other important aspects of participants' lives. One area was in relation to family.

12. There was some discussion on the interaction between experiences within the group and those with **family and friends** outside of the group. This was with regard to the limited understanding some family and friends had of the impact of the cancer diagnosis and journey and this was contrasted with the support provided by the group.

We can't talk the same language with our friends – they probably don't understand but, when we talk there [in the group] we know everyone is going through the same thing and you can understand and relate to things and you get feedback – nodding and support which is good. Friend say 'be strong' but do they really know what I am feeling? They don't and because they don't, you can't open out to them. Even family, extended family, I don't think they know how much we're going through. But in a lung support group, you open up, you cry and you know that they are there for you. That's the difference.

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The information gained in the group also helped one carer to prepare family members for the impending death of a loved one.

I feel the knowledge I gained from the group helped me to understand that [patient] was not going to get well and therefore I could help my family to accept and cope better with his final weeks while acknowledging the inevitable outcome

13. Another outcome of group attendance was that it **influenced communication with health care professionals**. Participants reported using the information gained in the group to initiate more informed discussions with their health care professionals. Some participants reported hearing about a particular drug or treatment then going back to their doctor to discuss whether or not it would be useful in their situation. The group discussion even helped to remove some reservations about contacting their health professional. In this way participants reported becoming more proactive about their health as a result of their involvement with the group.

14. And in these ways the support group appeared to contribute to a **sense of empowerment** or control in their lives.

[Belonging to the group] It empowered me a lot. It has also given us opportunity to have second opinion, and have access to professional people, that wouldn't have normally. It's great from the point of view we know what is out there now. We just feel that we have a lot more choice at our fingertips.

15. Of particular note in this group was the chance to **give back to the group**. Whilst a couple of participants reported to what degree they enjoyed feeling that through their experiences they could help others on their journey. One participant had become an important role model within the group, however being that role model also had its negative sides as well. It appeared that being the person to whom others looked up, in some way appeared to be a barrier to the participant expressing concerns or fears. She also felt a great burden when she had to tell the group she had a progression of her cancer.

16. Others identified **challenging experiences within the group** included being confronted with members who were very sick or reporting bad news. It was also conceded that the death of a group member presents a challenge.

On the negative side, it is very, very hard to watch people in the group pass away when you have been attending the group for a long time. The death of members plays a profound role on the remaining patients mental health.

Whilst the sadness associated with the death of a group member was discussed, there was also some acknowledgement that it was part of the cancer journey.

Yeah, there are times when we get upset like when [group member] passed away; we were very upset that night. [Patient] had a very restless night but then we said 'that's life.' You accept it and live with it. Then when we came there, we got more encouragement – people are in the same journey

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Another participant reported that the death of the group member improved the closeness of the group.

... we have lost a few members just recently, but even that doesn't sort of detract from the group it sort of makes you feel even more closely. It's interesting that when your losing someone ... they were all personalities and people and partly family

For others commenting in the questionnaire, the positives outweighed the negatives.

I have grown so much from the time I was diagnosed. The group has offered me so much support and hope and I felt sad when the journey ended for some.

There were a few personal challenges. One carer felt the group was too much about patients and there should be more emphasis on the needs of carers. Another thought that it would be useful to discuss some of the more emotional or existential issues and take some of the focus away from treatment and information. Other challenges were described when people do not identify with others in the group or feel in anyway separate from the group. This was reported by one participant who was still going through chemotherapy whilst others had finished.

Within the interviews there was a great sense of seeking out as much information as possible and this was reflected in some of the areas for improvement for the group. There was a preference expressed by some participants (patients and carers) for more involvement of health professionals as guest speakers, including a lung surgeon, medical oncologist, respiratory physician, and physiotherapist. Sometimes this was a result of participants feeling that they did not get adequate time with their own health professional or felt that their health professional was very busy and so participants reported leaving consultations with unanswered questions or concerns.

Further indications of the desire for even more information included a suggestion of more structure to the meetings to allow for "more formal exchange of knowledge" and one participant suggested developing a database of papers with a number of sub-categories, for example, "solid oncology papers" and "herbal remedies." There was also a call, by one questionnaire participant, for the group to be more involved in advocacy, specifically in lobbying for more research and development funding, access to latest technology and lobbying for more rapid acceptance of new drugs by the Pharmaceutical Benefits Scheme.

One questionnaire responder suggested

the government [needs to] recognise that quality of life means providing support for patients and carers and is a vital part of peoples lives. It helps them live and die better

Participants commented on the stigma of lung cancer and this was a common topic of discussion in the group. The majority of lung group patients were non smokers or never smokers.

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3.3 Combined questionnaire results

Reasons for attending the Cancer Support Group

Table 6. 'Significant reason' ranked (N=27)

Item	'Significant reason'	
	n	%
Hearing about current medical research	25	92.6
Knowing that I am not alone	25	92.6
Talking about my feelings regarding cancer	24	88.9
Getting information on how to reduce or control side-effects	24	88.9
Relaxing with others who understand my experience because they are going through the same thing	24	88.9
Getting information about making my lifestyle healthier	23	85.2
Becoming more informed about the drugs used in cancer treatment and their side effects	23	85.2
Learning how to talk with my doctor and other health care professionals	23	85.2
Learning what to expect from chemotherapy and radiation treatments	23	85.2
Learning about healthy eating, nutrition and helpful dietary hints	22	81.5
Talking about my fears	22	81.5
Learning how other group members deal with their problems	22	81.5
Developing caring friendships with other cancer patients in the group	22	81.5
Discussing issues related to death and dying	19	70.4
Learning about other healing practices (like acupressure, Qi Gong, herbs and vitamins)	19	70.4
Learning and practicing relaxation and meditation	16	59.3

A 'significant reason' is defined, for the purpose of the analysis, as a *Very Important or Important* reason for attending the Cancer Support Group. Of the 16 reasons listed in the questionnaire, the five most frequently rated as *Very Important or Important* reasons for attending the Cancer Support Group include (see Table 3), in order:

- Hearing about current medical research (v. slightly stronger response in lung group)
- Knowing that I am not alone
- Talking about my feelings regarding cancer
- Getting information on how to reduce or control side-effects
- Relaxing with others who understand my experience because they are going through the same thing

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For the purpose of the analysis, an ‘unmet reason’ is where the *Very Important* or *Important* reason for attending the Cancer Support Group is only *Somewhat Satisfied by the group*. Of the 16 reasons listed in the questionnaire, the top three reasons’ for attending the Cancer Support Group that were only *Somewhat Satisfied by the group* include (see Table 3), in order:

1. Hearing about current medical research
2. Getting information about making my lifestyle healthier
3. Discussing issues related to death and dying

Table 7. ‘Unmet reason’ ranked (N=27) or Somewhat Satisfied

Item	‘Unmet reason’	
	n	%
Hearing about current medical research	7	25.9
Getting information about making my lifestyle healthier	7	25.9
Discussing issues related to death and dying	7	25.9
Learning and practicing relaxation and meditation	6	22.2
Talking about my feelings regarding cancer	5	18.5
Learning about other healing practices (like acupuncture, Qi Gong, herbs and vitamins)*	5	18.5
Learning about healthy eating, nutrition and helpful dietary hints	5	18.5
Getting information on how to reduce or control side-effects	5	18.5
Becoming more informed about the drugs used in cancer treatment and their side effects	5	18.5
Talking about my fears	4	14.8
Learning how to talk with my doctor and other health care professionals	4	14.8
Relaxing with others who understand my experience because they are going through the same thing	3	11.1
Learning what to expect from chemotherapy and radiation treatments	3	11.1
Learning how other group members deal with their problems	2	7.4
Knowing that I am not alone	2	7.4
Developing caring friendships with other cancer patients in the group	1	3.7

NB* This was **the only ‘significant unmet reason’** (i.e., rated as a *Very Important* or *Important reason*, for attending the Cancer Support Group, and *Not Satisfied by group*) as indicated by one participant.

When comparing all 16 *Reasons for attending the Cancer Support Group* using chi-square tests, the proportion of people who had/have cancer with ‘unmet reasons’ were not statistically significantly different from the proportion of partners/carers with ‘unmet reasons’.

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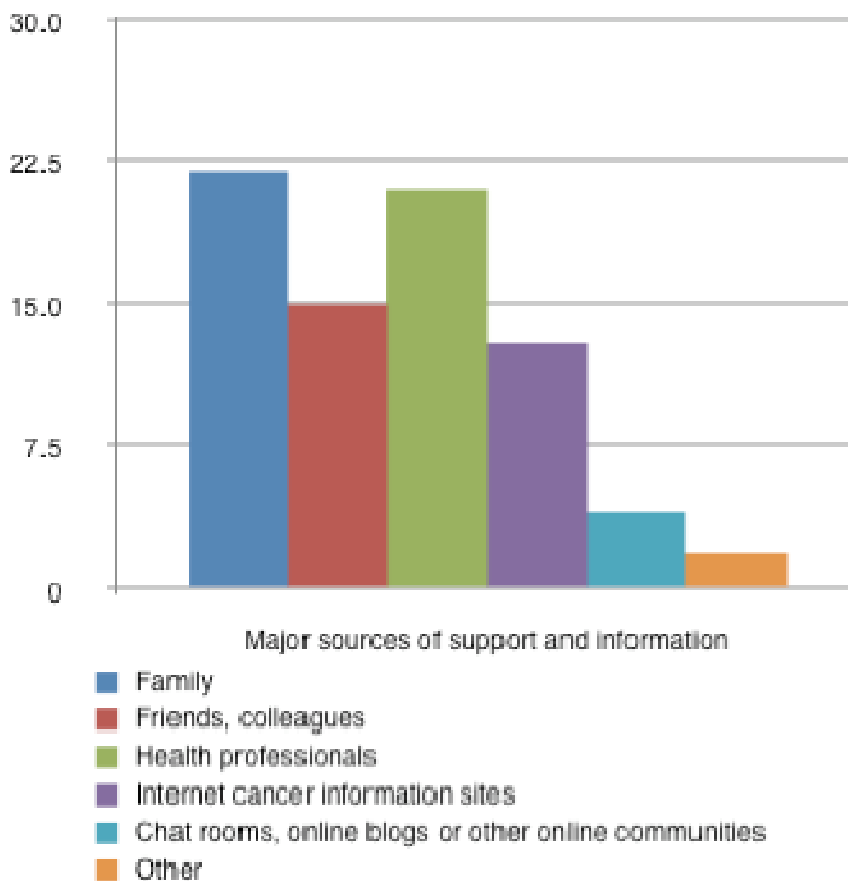
Additionally, the proportion of people who attend the gynaecological cancer support group with 'unmet reasons' were not statistically significantly different from the proportion of people who attend the lung cancer support group with 'unmet reasons'.

Ten of the 27 Cancer Support Group participants that took part had no 'unmet reasons', while 44.4% (12) of participants had three or more 'unmet reasons' (see Table 4).

Major Sources of Support

When asked to indicate other major sources of support and information, besides the support group attended, the majority of participants (92.6%; 25) indicated they have multiple sources of support and information (see Figure 8). Participants were prompted to indicate more than one source of support and information. Other sources of support and information include other support groups.

Figure 8 Major sources of support and information, besides the support group

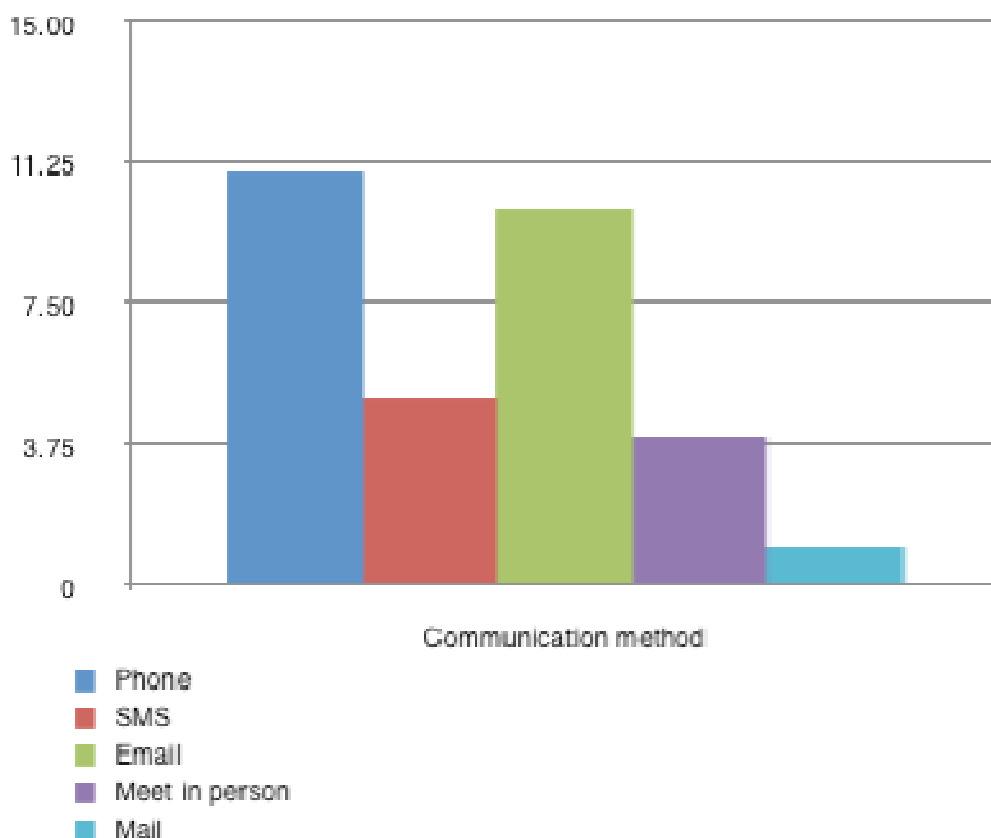


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Contact with group members or facilitator between support group meetings

Fifteen participants indicated they contact the group members or facilitator between meetings (see Figure 9). A third of these participants (33.3%; 9) indicating they use multiple methods of communication (see Figure 3). The two most common communication methods between meetings include phone (40.7%; 11) and email (37%; 10). The members of the gynae group reported a higher rate of contact between meetings. This may perhaps be attributed to meeting monthly as opposed to fortnightly also being a young communicative group of women very familiar with email and SMS.

Figure 9 Method of communication used



Most helpful aspects of the support group

Participants were asked what they considered personally as the three most helpful aspects of their support group. Responses were qualitatively analysed, clustered and summarised. Participants' responses can be grouped into eight categories:

Support – support from others in the group

Not alone – participants knowing that they are “not alone”

Information – this includes information sharing with fellow participants, guest speakers, facilitator regarding research, treatment, side effects

Friendship – forming friendships with people within the group

Emotional – being able to discuss feelings in supportive environment

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Community – sense of community; meeting people who have/had similar experiences

Caring – being with people who are understanding, compassionate and caring

Other – this includes comments about the facilitator, food, and encouragement from others doing well

Information was the most commonly commented category, with approximately 37% responses by participants who had/have gynaecological cancer, 38% of responses by participants who had/have lung cancer and 33% of responses by participants who are a partner/carer of people who had/have lung cancer.

(Full quantitative and qualitative reports available on request).

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4. FINDINGS

The findings report directly against the project aims, outlined on the first page of the document.

4.1 The activities of the project have **increased awareness of support services, referrals to support groups, and attendance at Sydney Adventist Hospital (SAH) support groups for people with lung and gynaecological (gynae) cancers and their carers**. The increased awareness and referral to the support services have been achieved through a range of activities:

- Collaboration with key health professionals in both the lung and gynae cancer areas, including the Australian Lung Foundation and the Gynae Oncology teams at Westmead Hospital, Royal Prince Alfred Hospital and the Royal Womens Hospital and others
- Collaboration with cancer agencies: Cancer Australia, Cancer Council NSW, NSW Cancer Institute, Cancer Voices, Ovarian Cancer Australia and others
- Website placements
- Media coverage of key events
- Direct mail to key health professionals for assistance with referral and promotion
- Circulation of promotional fliers within the community
- Forums and information activities

Due to the establishment of a system to track people with lung or gynae cancers attending or making enquiries about support services at the CSC, a 171 % increase has been measured in the past two years. While the number of cancer patients attending these support groups as a direct result of encouragement from their oncologist or general practitioner is not yet significant, there is a groundswell of growing awareness of the lung and gynae support groups at the SAH and many patients report seeing the SAH promotional fliers in treatment centres and doctors rooms. The patients themselves are also informing their health professionals of the benefits of the groups.

The SAH Lung Cancer Support Group is still believed to be the only face to face group in operation in eastern Australia and in spite of nineteen deaths in the past two years currently has twenty people on the roll, up from three in its first year. Fifty two people with cancer have ever attended the group. The Gynae Cancer Support Group was established as part of this project and in spite of four deaths has grown from four women at the initial meeting to twenty on the current roll. Twenty five women have ever attended this group.

4.2 Specific programs and workshops were developed to specifically meet the differing needs of each of these cancer groups.

- Lung Cancer Forum 2007
- Lung Cancer Forum 2008
- Gynae Cancer Experiential Program (six week) 2008
- Gynae Cancer Forum 2009
- What Else Can Help? 2009

Invited speakers presented workshops at regular meetings on a range of topics including:

- Gynae Cancer Q &A,
- Nutrition and healthy lifestyle
- Mindfulness meditation,
- Embracing life, facing death
- Resilience and coping after loss
- Advocacy, the role of Cancer Voices

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- Fundraising, GO Research Fund activities
- Physiotherapy: Improved breathing with Lung cancer

The provision of information has been highlighted as one of the major reasons for attending these support groups so it has been seen as essential to continue to provide programs and information workshops specific to the needs of each group. The larger forums have also been highlighted as an excellent strategy to promote the activities of the SAH CSC to the wider community and thus to potentially raise awareness of the support group activities available. Careful planning and regular consultation has taken place with group members to identify their precise requirements and all activities have been carefully evaluated and reported on providing an excellent framework for future activities. Financially, it should be noted that while medical officers and hospital staff do not charge, a small percentage of the speakers do need to charge for their time. While the project funding covered these charges, this becomes an issue when resources are not available.

4.3 The third aim was **to refine and evaluate the support group model** and make it available to interested parties. The attendances at the groups and the results of both the qualitative and the quantitative research would suggest this has been achieved. Caution needs to be taken to in any way suggest there is only one model as this is far from true. The SAH Cancer Support Group model very much meets the recommendations as outlined in the CCNSW publication, *Cancer Support Groups, A guide to setting up and maintaining a group* (CCNSW Guide). The model for the project was taken directly from the successful SAH CSC Breast, Prostate and Bowel Support Group model. The basis elements of this model are: open support group, scheduled meetings at regular intervals (often fortnightly), format designed to meet the needs of the specific group with core items of provision of: a safe, welcoming supportive environment and access to quality information. Two skilled facilitators with provision for their debriefing and supervision are essential. Besides meeting the basic recommendations in the CCNSW Guide, key aspects of the SAH model to highlight for this project include:

- The SAH has operated a stand alone cancer support centre, the CSC, for over fifteen years and consequently has a great deal of experience in establishing and maintaining a range of cancer specific groups
- The CSC provides a safe, warm and welcoming environment offering a wide range of activities free of charge as well as access to a well stocked library with books, CDs and DVDs.
- Both the gynae and the lung support groups are cancer specific and have largely attracted and maintained a membership of people with advanced cancer.
- Carers/partners are made very welcome at the lung group.
- Both groups have attracted a membership of people from a higher socioeconomic background than the NSW community, people who have placed great value on access to current, accurate information provided in a safe supportive environment
- Due to the reputation of the SAH, CSC, it has no difficulty attracting numbers of highly committed volunteer facilitators, often semi retired professionals with a range of experience, skills and time to bring to the role.
- Also due to the reputation of the hospital and its location in metropolitan Sydney, it has no difficulty attracting highly qualified oncologists, health professionals and healthy lifestyle specialists to speak at events.
- SAH CSC facilitators attend monthly supervision and have debriefing sessions after each meeting. These activities become imperative considering the challenging nature of role, in managing the negative news and the number of deaths in the groups.

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- SAH CSC facilitators for these groups monitor their members carefully, maintaining phone or email contact with those in declining health or with special needs.
- All CSC support groups are carefully evaluated annually, with participants asked to rate: venue, day, time, content, style, facilitator, facilities, activities and to make comments and recommendations for the coming year. This information is, in turn, used to plan the program for the coming year. All other activities are fully evaluated and guest presenters are informed of the evaluation results of their presentation.

While the two groups operate with the basic CSC support group model, the flexibility of the model has allowed it to adapt to the requirements and attributes of each group,

The features and attributes of the Lung Group:

- Fortnightly meetings
- Very experienced coordinator, very knowledgeable regarding lung cancer and treatments
- Information focussed group +++++
- Carers/ partners welcome, many attend
- Group breaks for last quarter to allow discussion of special needs of patients and carers
- Occasional guest speakers
- Over 75% participants with advanced lung cancer or mesothelioma
- Mixed gender
- Longer running, very close knit resilient group, very supportive
- Significant number of deaths

The features and attributes of the Gynae Group:

- Monthly meetings
- No partners/carers
- Female only
- Support and information focussed
- Regular speakers
- Facilitator very experienced in women's health
- Regular email/SMS communication between group members between meetings
- Recent advocacy/fundraising focus
- > 90% with advanced stage of cancer

These variations on the same model have been adapted to specifically meet the needs of each group and highlight the fact there is no "one size fits all". The members of both groups rate them highly in all surveys, in terms of meeting their needs. The larger percentage of men in the lung group may predispose it to being more "information focussed" but this is not proven. Also, perhaps the rapid progression of lung cancer in the final stages contributes to the desire for more and more information on what else can be done.

Perhaps the slightly younger age and higher education level suggests that the women in the gynae group obtain a good deal of information from the internet and chat rooms. This becomes evident during meeting discussions

In relation to the SAH providing for a higher socio economic clientele, it is essential to continue to lobby appropriate services to fund cancer support education for all health professionals to ensure that access to quality support and information becomes an integral part of holistic care for all Australians.

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4.4 Through their attendance at these SAH Gynae and Lung Cancer Support Groups, our research has demonstrated **an improvement in attendees perceived quality of life as well as their psychosocial skills to deal with life after a diagnosis of cancer**. The major benefits contributing to this improved quality of life and greater sense of control highlighted for both groups include:

- The feeling of not being alone, others "in the same boat."
- Access to quality information, including information sharing with fellow participants, guest speakers and with facilitator regarding research, treatment, side effects
- Friendship, forming friendships with people within the group
- Emotional, being able to discuss feelings in supportive safe environment
- High levels of support from others in the group
- Community, a sense of community; meeting people who have/had similar experiences, likened to a family or a club
- Caring, being with people who are understanding, compassionate and caring

5. RECOMMENDATIONS

It has been demonstrated that support groups fulfil a very real need for people with lung and gynaecological cancers particularly those with advanced disease and a subsequent poor prognosis. In order to establish a similar service, it is highly recommended that the CCNSW publication, *Cancer Support Groups, A guide to setting up and maintaining a group (CCNSW CSG Guide)* be followed. We would like to highlight a concise precis of core activities which we believe are essential to plan, develop, and operate an effective support group:

5.1 Needs assessment

Start by looking at these questions. Are you reacting to a perceived need? Are there sufficient numbers in your area for a cancer specific group? Is there a generic cancer support group in your area? How far is the closest cancer support group in operation? What other support services are available in your area? Where are the local hospitals, chemotherapy and radiotherapy centres where patients with this cancer may be treated? Is there a telephone support group available for this specific cancer? Is there an online support initiative? What model might work for your area?

5.2 Networking & collaboration

You cannot do it alone! It is essential to meet with as many health professionals, cancer patients and relevant others to further develop the concept of the group and what it might look like, where and when it might operate, who might be involved and other details. Collaboration and consultation are essential to promote a feeling of ownership by all involved and a very real desire to assist in every way to see the idea develop and succeed. Ideally you will form a working party with representation from each group to help develop, implement and evaluate your new support group.

5.3 Planning & development

See Chapter 3 of the CCNSW Cancer Support Groups guide, which will assist you along each step of the way. You will now work out the how, when, where and why, of your venture and what model you might commence with. Remember your group must be accessible, appropriate and affordable (ie fuel

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costs, fares, car parking charges and the like). Who will facilitate your group and what training and support might they need now and in the future. Where might you source funds to operate your group? Caution is urged in suggesting there is “one size fits all” and there is now a range of successful “mix and match” models such as operating a closed group followed with gazetted information sessions of interest to all whether with early or advanced cancer, also perhaps craft days or even social outings. Contact the Cancer Council NSW for further information regarding other models. Be flexible!

5.4 Data requirements

Use technology to assist you! First establish a method to track the details of all who make enquiries about your service. Develop a database for registering members details so you can contact as many as possible by email and circulate newsletters or other information. Another database will be needed for health professionals, treatment centres, community centres. This will be used to circulate information about your service and promotion of specific activities. These invaluable tools will also enable you to track the details of your activities and evaluate some of your strategies.

5.5 Promotion

People need to hear about your service! A great way to launch it will be to have a Forum with expert specialists in the field addressing the group. Include a question and answer session and try to have a couple of patients and perhaps a partner/carer, talking about their own cancer journey. An event such as this provides a platform for a very focussed promotion. Develop a promotional flier (do it yourself on very bright paper if limited resources).

- Circulate flier widely - all hospitals, health professionals rooms, treatment centres, community centres, libraries, pharmacists
- Media - local newspaper, radio
- Website - ideally develop your own and link it to relevant others. Certainly notify peak bodies and other service providers of your new service so then can list the information on their website eg CCNSW, ALF for lung cancer, Ovarian Cancer Australia and the National Breast & Ovarian Cancer Centre for ovarian cancer. Also provide your service details for listing with your local area health service.

Don't forget that after your group is launched, you will need to continue to attract new members so an ongoing promotion plan also needs to be developed. Letters of invitation to patients leaving hospital can be a great initiative if supported by a friendly Nursing Unit Manager.

5.6 Evaluation

The really important part! Following your first meeting (see *CCNSW CSG Guide* pp.24 - 26) when you will have found out what the group wants, you will meet with your Working Group to evaluate the meeting and develop a proposed schedule for the next six months. Constantly evaluating your service helps check that you are on track in meeting the needs of the group, as well as informing you regarding speakers or other initiatives they may be interested in.

6. CONCLUSION

It has been demonstrated that support groups fulfil a very real need for people with lung and gynaecological cancers particularly those with advanced disease and a subsequent poor prognosis. This project has shown that attendance at a support group can improve the quality of life for both the person with cancer and their partner or carer.

The major outcomes for participants, regardless of whether lung or gynae cancer patient, male or female, patient or carer, were – a feeling of not being alone; access to quality information; the support of others who are understanding, compassionate and caring; a safe environment where feelings can be fully discussed; and a strong sense of family or community.

The project has identified the key components of establishing and maintaining groups for both lung and gynaecological cancers as: networking and collaboration; planning and development; establishing and maintaining data requirements; promotion; implementation and evaluation. The need for skilled facilitators with very good interpersonal skills was highlighted, with quality supervision essential. The need for a flexible model is very important as well as the constant monitoring of the support activities to ensure the needs of the group are being met.

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