

New study highlights only one quarter of referrals to cancer support groups come from health professionals.

In NSW, around 28,000 people are diagnosed with cancer every year. Approximately half will still be living five years later. Many studies have documented the psychological distress associated with diagnosis. Psychosocial support has been found to reduce this distress.

What's more, it clearly has a positive impact on quality of life and emotional well-being yet only a small proportion of health professionals are referring cancer patients to support groups even though they have been shown to offer the support cancer patients need.

A two-year Cancer Council NSW funded study into the nature and effectiveness of support groups for people with cancer in NSW, was completed this year. The study was conducted by researchers from the University of Western Sydney, the University of Sydney and Westmead Hospital.

A state-wide audit showed that support groups are an integral part of the cancer experience for many people with cancer and their carers throughout all areas of NSW. One hundred and sixty seven groups participated in the study.

The study was longitudinal and involved both qualitative and quantitative investigations. Participants were followed up at six and twelve months to investigate the impact of group characteristics on outcomes. The study showed that well-being improved over time. It also showed that people attending groups had lower levels of anxiety and depression than those not attending groups.

Answers to the following questions are derived directly from the research findings.



WHY ARE WE TALKING ABOUT THIS?

Participants in the study were asked how they learned about their cancer support group. Most commonly, people find out about groups through a friend or newspaper. Only a quarter cited their health professional as a referral source.

Meanwhile, a health professional's opinion regarding the value of support groups has been identified as an important factor in a patient's decision to join, or not. Many participants said that they wished they had known about support groups early in their cancer experience, but no health professional recommended attending one.

You have a vital role to play in recommending support groups and encouraging patients to investigate them. You can't do this unless you are armed with the facts: hence this conversation.

WHAT IS A CANCER SUPPORT GROUP?

Support groups are characterised by small numbers of participants, face-to-face interaction, emphasis on personal participation, voluntary attendance, acknowledgement of the purpose for the meeting and the provision of emotional support. This study included any group that identified itself as a mutual support group that included more than two people meeting together.

Support groups are often undertaken in a voluntary capacity with little direct financial support and variable formal input from health services and cancer organisations.

WHAT HAPPENS IN A TYPICAL SUPPORT GROUP?

Formats vary, but typically support groups provide an opportunity to share feelings with others who are "in the same boat" in a supportive atmosphere. Groups also offer a place where members can exchange information, learn coping strategies from others and develop a sense of cohesion with peers.

A single meeting could involve laughter, tears, connection, empathy, love and acceptance as well as learning something new.

More than 75% of groups in the study regularly invite speakers to present topics of interest at meetings. Guest speakers include doctors, nurses, psychologists, dietitians, naturopaths and pharmacists.

Venues for meetings fall into two broad categories – those held in community settings and those held in hospital or health care settings. Facilitators can be health professionals or non-health professionals; people with personal experience of cancer, or not; trained or untrained. All are effective.

WHAT MAKES A "GOOD" SUPPORT GROUP?

Participants say a good support group is largely one where there is a feeling of a unique bond with other people in a similar situation to themselves. Differences in personal background, type of cancer and treatments are outweighed by the commonality of experiences.

Whether the group leader has training or not, or has had cancer or not, are not associated at all with satisfaction with the group leader. Leaders are valued for their caring, dedication and availability, independent of their training or cancer experience.

The study showed that people who attend support groups for heterogenous cancers have greater improvements in anxiety and satisfaction with the group, than those attending groups for site-specific cancers.

WHY DO PEOPLE JOIN A SUPPORT GROUP?

The experience of a physical illness has been identified as the primary reason for participation in any kind of support group. The main factor associated with support seeking is anxiety related to both the illness itself and the social burden of the disease. People who attend report that they expect to receive encouragement and optimism; relief from fear, depression and stigmatisation; inspiration, hope for improved survival and quality of life; and advice about improving outcome and maintaining a positive attitude.

The top five reasons participants give for joining a support group are:

- knowing they are not alone
- hearing about current medical research
- becoming more informed about the drugs used in cancer treatment and their side effects
- learning about and comparing how other people deal with cancer
- relaxing with others who understand their experience because they are going through the same thing

Does the experience live up to those expectations?

A SENSE OF BELONGING.

The support group operates like a surrogate family. People describe the group as a supportive and caring environment where individuals feel accepted for themselves, where they feel safe to express their true feelings without protecting others, and where there is empathy and understanding in response. Group members feel they are not alone. The sense of community and identification with others who have similar experiences, and who are not afraid to talk about cancer or death, results in a feeling of being cared for; of being "held" by the group.

TACKLING ISOLATION.

A cancer diagnosis is a major life event. It can result in shock, disbelief, anger. Feelings of "why me?" are common. It can also be very isolating if the person has little experience with cancer or no knowledge of support available for the "cancer journey". Isolation can lead to distress and fear and feelings of being "abnormal".

"Now you can talk to somebody about it and you meet up with people who are worse off than yourself. The isolation's gone."

The group anchors people. A sense of community develops through sharing feelings and experiences in the group, and serves to unite people as they get to know intimate details of each other's lives. Connections between people are established and continue to function as social support between meetings. Relationships between group members become a therapeutic tool.

Why do they stay? What is it that people value so much about their group?

EMPATHY.

Everyone at a cancer support group has some experience of cancer. This creates powerful empathy within the group.

People outside the support group may dismiss feelings or have difficulty understanding the experiences of people with cancer. In the support group, participants are not patronised or told to be optimistic. They are heard and understood. Empathy and understanding allow group members to be accepting and tolerant of emotion – without having to ask for an explanation of it, or offer a solution for it. Participants contrast this to experiences outside the group.

“The family don’t really understand what it’s like to have it thrown at you and then to have to learn to cope, but here you don’t have to explain.”

BEING CARED FOR.

Group participants are unequivocal in their experience of feeling cared for in the group. The caring received and given within the group is contrasted with roles and responsibilities in relationships outside the group, where it is perceived feelings must be contained, or others protected.

“I wanted a place where I could really talk about how I felt and I didn’t have to worry about hurting someone or protecting them. That’s really important.”

SAFETY.

One of the most frequent comments is that the support group is a safe environment where individuals can express feelings. In particular, people report feeling safe to discuss openly the ordinarily taboo subjects of cancer and death.

“It’s a very safe place to cry in.”

Clearly, families and other social support networks are very important. However, support groups are experienced as the safest place for the expression of emotion. Important in the group is the positive way in which people are encouraged to cope, in particular with negative feelings or issues.

“We’ve talked about death. You can’t talk about that anywhere else.”

HUMOUR.

One of the most striking features of groups is the level of warmth and humour between participants. Humour provides a positive context in which participants can relax and feel at ease. It is also an effective coping mechanism for dealing with adversity. It creates a sense of solidarity amongst group members and reduces self doubt.

“Sometime you’ve got to laugh or you’d collapse in a heap.”

SO WHAT IS THE IMPACT OF ALL THIS? WHAT ARE THE BENEFITS OF CANCER SUPPORT GROUPS?

Cancer support groups are clearly powerful agents for improving psychological well-being.

“We have got a bit of power back by realising we are not alone and realising our problems are common.”

Many participants describe positive changes in themselves, or changes in their lives, that occurred after they had been members of a group. These changes draw attention to improvements in psychological well-being, in particular those associated with feeling part of a community as opposed to being isolated or alone.

One of the major changes reported is an increase in empowerment and control over life. A common consequence of cancer is a feeling of loss of control over the body, which can influence all aspects of a person’s life. By attending the group, having permission to openly express feelings, as well as meeting and learning from others with similar experiences, participants report increased levels of control. They report feeling empowered both within themselves and in relation to their interaction with others, particularly health professionals, and their family.

“I was scared to ask my doctor or surgeon certain questions. I didn’t think I had the right. But I learnt through the group that I do have the right to ask. I then started asking my surgeon things which was good for me because it settled me in many ways.”

It is well established that helplessness and hopelessness lead to depression. Greater self-efficacy and a greater sense of control over life reduce anxiety and depression, and increase general well-being. Support groups clearly facilitate a sense of control over aspects of the cancer journey. It is not surprising to find that participants experience increased feelings of well-being after joining a group.



HOW DO SUPPORT GROUPS FACILITATE THIS POSITIVE EXPERIENCE?

There are three key mechanisms – modelling, information sharing and leadership.

“At first I thought cancer is really terminal but now I see examples, and then getting all this encouragement and support I’m no longer afraid.”



LEADERSHIP.

Group leaders vary in their training and experience with cancer, but consistently, it is their enthusiasm, caring and availability, which underlies the unconditional support received from the group.

Group leaders have formal and informal educational roles. They may organise guest speakers, teach helpful coping strategies, develop information packs, create a group newsletter or simply provide updates about cancer or research.

Effective facilitation of group meetings is a skill essential in any group setting. Facilitation skills identified by the researchers were inclusiveness, effective communication, organisational ability, and being “evocative without being invasive”.

MODELLING.

Positive role models are a powerful force. Modelling has been recognised as an important method for learning in a variety of contexts. Group members model strategies to help improve coping; they demonstrate that open expression of emotion and vulnerability is permissible and they show that it is possible to help others cope with their cancer.

Sharing experiences with others facing a common stressor is recognised as helping to normalise the cancer experience and reduce feelings of being atypical. Interviews with group participants showed that actually witnessing someone who has managed their cancer and is able to face their own mortality helps others to cope with their own cancer.

INFORMATION SHARING.

Support groups provide a place where information is shared about treatment, side effects and complementary therapies. People who are yet to make a treatment choice often discuss the decisions of others with a similar diagnosis. Many participants comment that one of the benefits of attending a support group is learning how to communicate with their health professional. Useful tips for communicating with health professionals are shared. One of the most common tips is to write a list of questions to ask health professionals. People often bring the answers back to the group for discussion.

IF THEY'RE SO GOOD, WHY DOESN'T EVERYONE WITH CANCER GO TO A SUPPORT GROUP AND WHY DO OTHERS DROP OUT?

The research identified four main factors which explain why some people do not attend cancer support groups.

1. They do not want to revisit cancer experiences and feel they have enough support.
2. Their personality or coping style means they have difficulty “opening up” and are fearful of exposure.
3. They are avoiding contact with cancer.
4. Wanting “people like me” and lack of awareness about groups.

These disparate factors need to be taken into account when assessing the needs of people with cancer or their carers, or when developing interventions.

The research shows that people who leave groups are more likely to have cancer that is no longer detectable, are more

satisfied in their communication with health professionals, have spent less time in the group, are more likely to have attended a group based in Sydney and a group that was hospital-based.

Dissatisfaction with a particular group is also a significant reason for leaving. This suggests the importance of finding the right group to suit the individual's needs or that cancer support groups may not be the most appropriate means of support for everyone. It's important for people to be aware of alternative avenues for support.

AREN'T THESE GROUPS UNDERMINING MEDICAL TREATMENT?

Some clinicians worry this may be the case, but the answer is no. They are actually supporting and complementing medical treatment. In fact, given the information sharing that goes on in cancer support groups, they tend to offer clarity about medical treatment. This may increase compliance. What's more, they empower patients to communicate with clinicians better.

OK. Where can I get more information? What other social support services are available for my patients?

Cancer Council website:
www.cancercouncil.com.au

Call the Cancer Council Helpline
13 11 20

The full range of local support services are outlined in
The Cancer Council's Support and Information Pack.

Call the Helpline for details.

