Educational Support Programme for Gynaecological Cancer Patients and Their Families

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In order to improve psychosocial support for gynaecological cancer patients and their families a project with educational and supportive group programmes was started. This article presents an evaluation of the project. The study group consisted of those patients and next-of-kin who wished to participate in the educational support group programmes ($n = 36 + 8$). Patients from distant parts of the catchment area who were not able to participate constituted the controls ($n = 25$). A graded Likert-like questionnaire and a short profile of mood state (POMS) were completed before and after intervention. Patients who actively chose to participate differed from the unselected control group even prior to educational intervention. In certain issues their perceived knowledge about cancer was inferior to that of the controls and they felt more confused and angry than the control group ($p < = 0.05$). After intervention, the patients in the interventional group reported a significantly improved level of knowledge about cancer than the controls ($p < 0.001$, group by time interaction). The qualitative section of the evaluation revealed that the most positive experiences coupled with participation were the information and knowledge received and the mutual understanding experienced together with the other group members.

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A diagnosis of gynaecological cancer can come as a great shock and can give rise to considerable personal uncertainty. One way of offering support and reducing the feeling of uncertainty is to provide information. A study of psychosocial predictors for adjustment to gynaecological cancer showed that there is a correlation between uncertainty and pessimism (1). Inadequate information resulted in a decrease in motivation to alter the situation. However, when the women had learned more about their illness and had acquired some knowledge, they reflected a more positive attitude towards both the current situation and the future.

A Swedish study by Lalos et al. (2) showed that most of the partners of the women felt that they had not been given basic information about the cancer and its treatment. Furthermore, the study revealed that some of the men wrongly believed that they had caused the cancer in their women and they also thought that cancer was transmitted by sexual intercourse. Both these misconceptions created barriers with regard to their sexual activity. Another study by Carlsson & Strang (3) found that patients also express misconceptions about cancer and cancer treatment.

During the past 20 years, many different support groups and educational groups for cancer patients have been initiated. The groups are of two main types. Many groups are mainly supportive and the patients have the opportunity to meet other patients in comparable situations and with similar problems and are encouraged to discuss thoughts, feelings and problems under structured conditions. Other groups emphasize information and education. It is well known that women, compared with men, are generally more interested in different kinds of support and educational groups (4–8). However, studies show that, if the educational aspects are increased, men are more inclined to participate (9).

A project run over 3 years was initiated to improve the psychological support to gynaecological cancer patients and their next-of-kin. Prior to its start, a prestudy was conducted in order to evaluate to what extent the patients and their relatives were interested in participating in such groups. Another aim was to determine which specific issues were of most interest (10). The support and educational groups were based on the results of the prestudy and were focused on education, this being defined as pedagogic groups. Education and knowledge might constitute a considerable psychological support in a period of crisis and uncertainty. Another important function is to exchange experiences with other patients in similar situations and this constitutes an important part of the aims associated with support groups (11, 12).

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Table 1

Demographic data

	Group members			Control Patients	
	Patients (n = 36)	%	Next of kin (n = 8)	(n = 25)	%
Age					
Mean	57		54	56	
Variation width	25–79		25–67	35–75	
Employment status					
Full-time work	5	14	3	0	0
Full-time sick leave	7	19	1	13	52
Retired	16	44	3	10	40
Part-time work	6	17	1	2	8
Others	2	5	0	0	0
Legal status					
Married or cohabiting	25	69		17	47
Single	4	11		0	0
Divorced	5	14		5	20
Widow	2	6		3	12
Relationship					
Husband			6		
Parent			1		
Children			1		
Education					
Secondary school	12	33	3	18	72
Upper secondary school	10	28	0	5	20
University degree	14	39	4	2	8
Cancer type					
Cervical cancer	3	8		4	11
Endometrial cancer	15	42		7	19
Ovarian cancer	15	42		13	52
Other	3	8		1	4

* Owing to occasional missing data in the questionnaires, the sum of the subgroups, might be lower than the corresponding total number of individuals.

The aim of the study was to evaluate whether educational groups have an effect on the perceived level of knowledge and, secondly, whether this has a positive effect on mood. Another aim was to investigate whether those who chose to participate differed from the control group in perceived knowledge and mood.

MATERIAL AND METHODS

The groups comprised 3–8 participants and a group leader (MC) attended every group session. In addition, a 'speaker', or resource person, participated in most of the sessions. The groups were mixed (patients and next-of-kin) or comprised only patients. Each group had seven sessions and each sessions lasted for 1.5–2 h. The patients were at different stages of their disease. Some were newly diagnosed, some had undergone treatment, whereas others had regular follow-ups at the out-patient department.

Issues that patients had previously (10) ranked as the most important were included:

- What is cancer and how does it affect your body?
- Different treatment modalities, their side effects and how to counteract them.

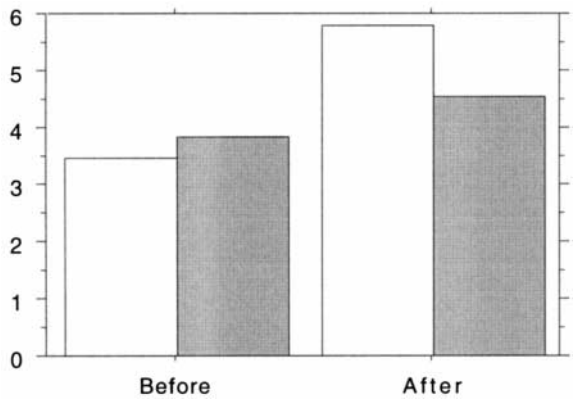

Fig. 1. Mean value of perceived knowledge, on a 9-point scale. Baseline and follow-up measurements for patients (white bars) and controls (black bars).

Table 2

The group members' and the controls' experience of their level of knowledge, on a 9-point scale, before and after the intervention. Time (p time) is the overall positive change over time (patient–control). Interaction (group × time) is the relative improvement, i.e. mainly how much more the patients improved compared with the controls

	Mean values						ANOVA effects		
	Patients		Next of kin		Control		p	p	p
	Before	After	Before	After	Before	After	time	group	group × time
I know a lot about cancer and how it affects the body	3.7	6.0	3.6	6.2	3.6	4.5	<0.0001	0.05	0.05
I know a lot about different gynaecological cancer types	3.2	5.5	2.1	6.0	3.4	3.7	<0.0001	0.05	0.001
I know a lot about different treatment modalities in cancer	3.5	5.6	3.6	6.3	3.5	4.5	<0.0001	NS	0.05
I know a lot about side effects and the treatment of side effects	3.5*	5.9	3.9	6.4	4.6	4.8	<0.0001	NS	0.001
I know a lot about pain and pain treatment	2.5*	5.2	3.2	6.2	3.7	4.2	<0.0001	NS	<0.0001
I know a lot about common psychological reactions in cancer patients	3.3	5.9	3.4	6.4	3.3	4.6	<0.0001	NS	0.05
I know a lot about coping with the disease	3.0	5.5	3.6	6.5	3.8	4.5	<0.0001	NS	0.01
I know a lot about common psychological reactions in families	3.6	5.6	4.0	6.4	3.7	4.6	<0.0001	NS	0.05
I know a lot about questions related to food intake and cancer	3.2	5.5	2.7	6.0	3.5	4.7	<0.0001	NS	0.05
I know a lot about dietary advice for bowel problems	3.4*	6.1	2.9	6.1	4.6	5.2	<0.0001	NS	0.001
I know a lot about relaxation and its benefits	3.7	5.4	3.9	5.5	4.0	4.7	<0.0001	NS	0.05
I know a lot about altered family life (partner, parents children, etc.)	3.7	5.8	3.2	5.9	4.0	5.2	<0.0001	NS	NS
Total	3.3	5.8	3.4	6.2	3.8	4.6	<0.0001	NS	0.001

* Significant between-group difference independent *t*-test $p < 0.05$.

- To live with a cancer diagnosis.
- Family relations and changes in roles.
- Pain and pain treatment.
- Diet and cancer. Diets for the treatment of gastrointestinal problems.
- Common psychological reactions associated with cancer and cancer treatment.

Four of the sessions were attended by 'speakers', a doctor (3 times) and a dietician (once). The participants were encouraged to deliver written questions to these sessions (the nature of the questions is reported elsewhere). The education concentrated on these actual questions and, thus, the sessions were of great interest to the particular group. On occasions when psychological issues were discussed, the approach was different and mainly characterized by discussions about the patients' experiences related to established crisis- and coping theories (13, 14).

The study had a quasi-experimental design. Patients and next-of-kin who lived relatively close to the hospital and had a reasonable possibility of participating were invited to the programme, and patients from more distant parts of the region who had undergone a 6-week course of radiotherapy were also invited to participate, thus making this a heterogeneous group. Some of the patients were severely ill, in a progressive phase of their disease, and could not therefore complete the programme. Only those patients and next-of-kin who participated in more than half of the sessions were included in the evaluation. The evaluation consisted of an interventional group of 36 patients, 8 next-of-kin (no statistical comparison) and a control group of 25 patients from distant parts of the region who were unable to participate due to geographic difficulties. The mean age was similar in both patient groups (interventional group 57 years and control 56 years) and somewhat lower for the next-of-kin (54 years). The patients diagnoses were quite similar in both groups except for a greater number of patients with endometrial cancer in the interventional group than in the control group (42% and 19% respectively) and the opposite trend for ovarian cancer (42% and 52% respectively). These differences were attributable to the recruitment to the control group (patients

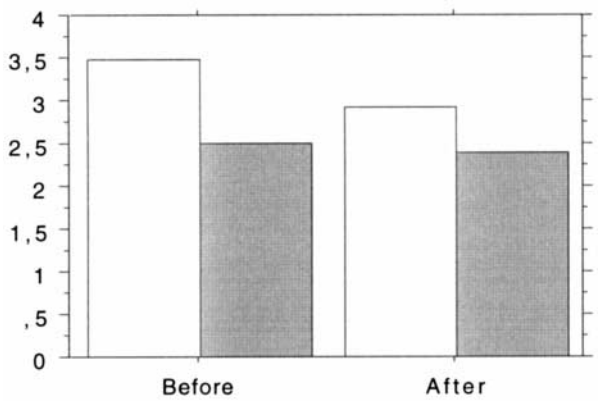

Fig. 2. Mean value of total score of a short profile of mood state (POMS) at baseline and at follow-up stratified for patients (white bars) and controls (black bars). A reduction signifies an improvement.

from distant parts of the region treated with chemotherapy). Demographic data are presented in Table 1.

A section of the evaluation was common to both the interventional group and the controls and one part was applicable to the interventional group only. The common part consisted of a short version of POMS (profile of mood state) with 6 questions in the LASA format (15, 16) and an instrument constructed for this study. In this instrument, the respondents graded their perceived knowledge on a 9-point scale (12 questions). The questions selected were based on a review of the literature and the authors' own experience (a cancer nurse and a senior gynaecological oncologist) and were presented in a combined numerical (9-point) and verbal scale of the Likert type and would therefore have a reasonable degree of face and construct validity. The interventional group completed the questionnaire at baseline and after the educational sessions were finished. The control group completed the questionnaire at the first treatment evaluation (baseline) and 2–3 months later.

An extra part of the evaluation that only the interventional group completed comprised open questions where they were free to describe the impact the groups had had. They were also encouraged to rank the two most positive and the two most negative experiences with the educational and support groups (see Tables 4 and 5).

The statistical analyses used were χ^2 (demographic data) and analysis of variance for repeated measurements and independent groups. Student's t-test was used for single comparison of baseline values. For the evaluation of total score of POMS, a reverted LASA was used for the variable 'energy' in order to include all LASA from negative to positive (15, 16). The qualitative analysis of the written comments was performed by content analysis (17).

RESULTS

Quantitative evaluation

There were some significant demographic differences between the patients in the interventional group and the controls. Those who participated in the groups had a longer formal education ($p < 0.01$) and had different employment status ($p < 0.05$, see Table 1).

In general, the participants of the interventional group reported that they had rather limited knowledge about the different issues before the start of the educational groups, but that their perceived knowledge increased significantly (Table 2). The control group had higher baseline values, but their improvement during treatment was rather limited (Table 2).

There were some differences in perceived knowledge at baseline (Table 2). Both groups improved at follow-up but the improvement was significantly greater for the patients in the interventional groups than for the controls ($p < 0.001$, group by time interaction). (See Fig. 1. and details presented in Table 2.)

Table 3

Mean values of group members and the controls for their experiences of mood (POMS), on a 10-point scale, before and after the intervention. Time (p time) is the overall positive change over time (patient-control)

	Mean values						ANOVA effects		
	Patients		Next-of-kin		Controls		p	p	p
	Before	After	Before	After	Before	After	time	group	group × time
Fatigued	4.0	4.0	4.1	2.9	3.1	3.2	NS	NS	NS
Anxious	3.7	2.9	2.9	2.9	3.5	2.7	0.05	NS	NS
Confused	1.7*	1.3	0.7	0.8	0.5	0.9	NS	NS	NS
Depressed	3.3	2.9	2.2	1.8	2.4	2.2	NS	NS	NS
Energetic	4.0	4.4	5.7	5.6	4.8	4.9	NS	NS	NS
Angry	2.0*	1.2	1.2	2.1	0.8	0.8	NS	NS	NS
Total	3.5*	2.9	2.6	2.5	2.5	2.4	NS	NS	NS

* Significant between-group difference independent t-test $p < 0.05$.

Table 4

The positive comments to the open questions

Categories	Comments	n
Information	'To be able to address questions about every aspect and still get an answer!' 'I have received answers to questions that others have asked and that I had not even thought about!' 'The opportunity to discuss and address questions to competent professionals.'	24
Education	'As a ''layman'' I feel that I know a lot now. Most of my questions have been answered and now I understand the important things about cancer' 'Good to hear other patients' reactions to their illness and also to understand how ''science'' looks upon reactions that cancer patients express. One becomes reassured that one has ''normal'' reactions.' 'To have achieved a greater knowledge about illness and its course and how to make one's life as good as possible now.'	22
Mutuality	'The need to meet others in a similar situation is great. One gives and takes and gains new perspectives about the problems.' 'It has been valuable for me because, being a patient at the ''outpatient chemotherapy unit'', there are few opportunities and little time to meet others in a similar situation. It is important to feel that you are not alone in the world with your problems. The groups have provided me with such a feeling of support and consideration both from patients and the staff.' 'To have experienced this special closeness with others, one is not alone.'	20
Positive atmosphere in the group	'The openness and the positive attitude.' 'The open and matter -of-fact attitude without it being frightening for the patients or next-of-kin.' 'To receive answers to important questions in a relaxed and neutral atmosphere.'	18
Feel reassured, reduced anxiety, security	'Reducing the frightening misconceptions about all these different matters about the illness.' 'I feel that information and patient education provide me with a feeling of security and reduce my anxiety.'	9
Better coping	'Very valuable when trying to cope with the situation today and in the future.' 'As I am single, I have really appreciated this group. To share with others thoughts and experiences, those thoughts that I have been pondering about myself, has given me a great amount of courage to carry on living.'	7

There was also an overall difference in mood (POMS) at baseline (t-test < 0.05). Patients in the interventional group reported a higher degree of confusion and anger at baseline (t-test $p < 0.05$). There was no significant improvement after the intervention for the patients compared with the controls for the total score of POMS variables at follow-up (see Fig. 2). There was a numerical improvement for the interventional group for the variables 'anxious', 'confused', 'angry', and when these three items were put together there was a significantly greater improvement for the interventional group compared with the controls ($p < 0.05$) (see Table 3 for details).

Qualitative analysis

The comments to the open-ended questions were generally positive; several participants could not list any negative comments. The categorization of the positive and negative comments can be found in Tables 4 and 5. Every categorization is followed by a representative quotation. Categories with many comments may contain several quotations.

The positive comments about the group sessions can be divided into three levels. The first one is about the conditions for positive effects and mainly the positive atmosphere of the groups. The second level is about the content and meaningfulness of the educational groups. Several participants commented that they had not only gained a better level of understanding and that their questions have been fully answered, but also that the contact with others was a very positive experience. The third level is about the effects of education and knowledge and of becoming acquainted with other persons in the same situation. Generally, participants reported that they felt more relaxed and confident and that they now have a better possibility of coping.

DISCUSSION

This evaluation is based on small, controlled groups but without randomization (quasi-experimental design), which tends to be a weakness because of generalized results. One of the strengths, however, is that the evaluation is based on the clinical reality—this kind of support group must be voluntary, patients cannot be allocated to such groups

Table 5

The negative comments to the open questions

Categories	Comments	n
The amount of time/too short sessions/too few sessions	'There was too little time for discussions after the teaching sessions.' 'When we had learned to know each other and had created a wonderful rapport, well that was when the groups were disbanded.'	11
Too small a group	'We were too few in the group. It would have been more valuable with more participants.'	6
Course of illness—the timing	'I would have preferred the education before treatment.'	5
A difficult reminder	'I was so sad about all the other participants who had cancer, especially the young ones. And now I think more about the risk of cancer dissemination in my own body.'	5
Too few next-of-kin	'It was a pity that so few next-of-kin chose to participate.'	3
Place	'The room and the location in the oncology department were not optimal	3
Too little of...	'The mental aspects and how to become mentally stronger should have merited more time.'	3

against their will. Moreover, the survey of support groups at 42 NCI centres (18) has great similarities with the current group.

The patients who actively chose to participate expressed a higher need of support than the unselected control group, regarding both knowledge and emotional support. Berglund et al. and Berglund (7, 19) report similar results and found in their studies of a rehabilitation programme for cancer patients that those who wanted to participate reported more problems at baseline than the controls.

Despite the fact that the participants had a significantly longer formal education in the current study, their subjective feeling of perceived knowledge about cancer was lower than that of the controls. Although this may seem contradictory, it is not unexpected and probably reflects the fact that persons with a higher degree of education are more prone to use information-seeking as a coping strategy (20). In fact, it is unlikely that these patients have less actual knowledge than the others. On the contrary, the study by Streptoe et al. (21) showed that those with the best actual knowledge were more dissatisfied with the information given.

At follow-up, the participants reported that they had gained a deeper understanding of cancer and cancer treatment. Furthermore, patients in the control group perceived that their knowledge had increased with time but the difference was significantly greater for the interventional group. Berglund et al. showed in their studies (7, 22) that patients in the rehabilitation programme were more satisfied than controls. The experiences from other education groups are similarly positive (23–25). In the study by Cain et al. (23) using an experimental design, the psychosocial effects of information were investigated. The results were strongly in favour of actively planned, structured information. An interesting finding was that the effect was comparable between those who received individual information and those who received the more cost-effective group information.

Concerning mood, as reflected by short-POMS, there were no significant differences as in improvement (before–after), this finding is in good agreement with similar studies (7, 22, 25), i.e. patients are satisfied and content with the educational groups, their perceived knowledge has increased, but this is not reflected in specific variables such as 'anger' or 'energy', and so on. Taking into consideration all the other concomitant factors, such as ongoing treatment, the lack of significant differences is not surprising.

Many of the comments on the open questions strongly indicated that the participants were very satisfied with the opportunity to address all kinds of questions in a relaxed and unrestricted atmosphere. We think that it is necessary to be explicit and to assure both patients and their families that the staff have the time and are interested in answering their questions; not only direct patient-related questions but also questions about cancer and treatment in general, since this kind of knowledge facilitates the coping process. For patients and next-of-kin who require a deeper understanding, educational support groups are an effective and even a cost-effective way of providing knowledge and support. One advantage is that the participants realize that they are not alone but that their questions and experiences are shared by others. Moreover, they learn from the questions that are addressed by other members of the group. In our experience patients who have been dissatisfied with their treatment and have had follow-up visits for 1–3 years also benefit greatly from educational sessions. Once they have received proper explanations to their questions/misconceptions, they feel relieved and can go on with their lives without this burden of uncertainty.

Conclusion

Patients who chose to participate in an educational and support programme differed at baseline from the unselected control group in that they expressed a lower perceived level of knowledge and more confusion and anger than the controls.

After the intervention the participants felt more informed, perceived a deeper knowledge about cancer compared with the controls.

The most positive experience was gaining new knowledge as a basis for coping and sharing personal experiences with other participants.

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