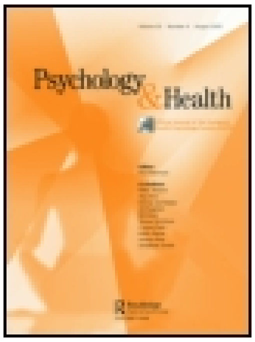

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CANCER COUNSELLING IN THE UNITED KINGDOM

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A national survey of 289 people from a variety of professions (nurses, social workers, clinical psychologists, psychiatrists, etc) involved in counselling cancer patients and their families within the United Kingdom obtained a response rate of 82%. The primary findings discussed in this paper cover a range of issues, including the working conditions and responsibilities of the counsellors, what professional qualifications they possess, the extent and availability of supervision and support, as well as the types of counselling intervention employed. Particularly disturbing was the fact that only 25% of our sample had any recognised formal counselling qualification and that 75% did not belong to any professional counselling organisation. In view of the wide diversity of qualifications, salary scales, responsibilities and working conditions and practices amongst the respondents, we propose that the National Health Service (NHS) should establish clearer guidelines as to the minimum acceptable qualifications for people employed as oncology counsellors, and that more adequate provision and resources are made available for training and supervision.

KEY WORDS: Cancer, specialist nurses, counselling, training.

INTRODUCTION

In recent years, awareness of a multitude of social and psychological problems that face people given a diagnosis of cancer has been steadily increasing (Maguire, 1985; Fallowfield, 1988a). One response to this has been an increase in the number of people employed in some capacity as counsellors, and many clinicians now view the oncology counsellor/specialist nurse as an invaluable, integral part of the health care team. Whilst the nature of the counselling/psychotherapeutic process itself has attracted much attention in the psychological literature (Kelly, 1955; Rogers, 1958; Jackins, 1964; Dryden, 1989), there have been few systematic attempts to evaluate its efficacy in interventions with cancer patients reported in the medical literature (Gordon *et al.*, 1980; Maguire *et al.*, 1980; Spiegel *et al.*, 1981, 1989; Linn *et al.*, 1982). Results from studies that have been conducted are equivocal (Watson, 1983; Cunningham, 1988), although patients themselves provide a great deal of anecdotal evidence attesting to the benefits of having had access to a counsellor. One of the reasons for the failure to produce evidence that counselling "works" is the difficulty in determining what outcome measure(s) ought to be used. Relying entirely on subjective anecdotal reports from groups of individuals who felt satisfied with their counsellor is not rigorous enough to convince those of a more sceptical disposition. However, expecting large differences in psychiatric morbidity between counselled and non-counselled groups seems too gross a measure; the benefits of counselling to patients may be significant, but too subtle to produce differences in the measurement of clinical anxiety and depression for instance. Another reason contributing to the difficulty in demonstrating efficacy undoubtedly has been the lack of specific information as to who is providing counselling, what qualifications the counsellors have and what theoretical models, if any, are being employed. We also have little information about other issues such as the nature of the goals pursued in the counselling relationship, where the counsellors are based, how they obtain referrals, how these posts are funded and what support and supervision services are available (Fallowfield, 1988b).

As well as the whole issue of evaluating the effects of counselling services on particular patient populations, of practical importance in its own right is the question of how counselling provision is organised. At present there is no official professional counselling organisation within the National Health Service (NHS), nor is there a common code of practice. No central register of oncology counsellors exists and unlike many other countries in Europe, anyone can call themselves a cancer counsellor (Fallowfield, 1988b). If the cause of counselling within the total spectrum of health care is to be advanced on a rational basis, then there is an obvious need to understand how the provision of counselling is currently organised, so that this can be made as efficient and effective as possible, from the point of view of both the counsellors and their patients. This will in turn make the task of assessing the effects of counselling all the more easier by a more rigorous control of what is being evaluated in the name of counselling.

To date little information is available regarding the nature, scope and extent of counselling provision in the British National Health Service (NHS). Breakwell and Alexander-Dann (1989) have recently published the results of a survey of District Health Authorities in Britain, which looked at how responsibility for counselling was spread throughout the range of occupations in the NHS, how this provision was budgeted for and the counselling qualifications expected of each group. The response rate for their study was disappointingly low (48%), allowing few firm conclusions to be drawn, but relevant issues bearing on our own work are discussed later in this paper.

The current study reported here is a survey of oncology counsellors and specialist nurses working with patients with cancer in the United Kingdom. We believe that the putative benefits of counselling patients with cancer cannot be properly appraised until certain basic questions have been addressed, namely: How many posts are in existence? What qualifications and training have counsellors had? How are these posts funded, i.e. from NHS, research or other charitable funds? How and by whom are patients referred for counselling? What support and supervision is available to the counsellor? What are the primary difficulties of the role? What counselling models and/or techniques are being employed?

METHOD

Design

Prior to sending questionnaires to prospective respondents, advertisements were placed in a number of professional journals (Journal of the British Association of Counselling, The Psychologist, Counselling Journal of the British Psychological

Society Counselling Section, Nursing Standard and Professional Nurse), in an attempt to put the researchers in touch with people whose work with cancer patients involved counselling as a significant component. In addition to this, lists of potential respondents were supplied by the British Association of Cancer United Patients, Westminster Pastoral Foundation, the British Psychosocial Oncology Group, Cancer Relief and the 1988 Counselling and Psychotherapy Resources Directory, produced by the British Association for Counselling. Finally, participants at the Oncology Nursing Society's 1986 Annual Conference were contacted to ascertain their suitability to be involved. A substantial degree of overlap in the names obtained from these various sources occurred. In all, throughout England, Scotland, Wales and Northern Ireland, 289 potential respondents were identified as being suitable for inclusion in the survey. We were aware that many health care professionals other than those contacted by us provide counselling during the course of their work. However, we were interested in obtaining information from people who were employed primarily as "counsellors." Thus, certain professional groups such as general practitioners or clinicians working in hospices may appear under-represented.

Procedure

Following initial piloting, a 35 item questionnaire was sent to all potential respondents together with a covering letter explaining the purpose of the study and the intended use to which the results would be put. A pre-paid addressed envelope was supplied for the return of completed questionnaires. Approximately one month after the initial mailing a reminder was sent to those people from whom replies had not been received.

Statistics

Comparisons between groups identified within the survey have been analysed using Chi square statistical tests.

RESULTS

Response Rate

A total of 219 completed questionnaires were received from the 289 initially sent out, giving an initial response rate of 75.8%. However, 17 of the respondents indicated that they did not consider their duties to fall within the remit of the study. A further 4 of the 289 were uncontactable from the most recent address. One person was unable to complete, owing to sickness. Eliminating these from the total gives a revised completion rate of 82% (219/267). Only 2 people refused to participate. The sample consisted predominantly of females (89% to 11% males). The authors suggest that this high response rate allows a good degree of confidence to be placed in the generality of the following results.

The Counsellors

Described by their current job titles, our sample comprised 124 nurses (57%)—(includes 15 nurses (7%) who described themselves as nurse counsellors), 31 social workers (14%), 20 designated oncology counsellors (does not include the nurse counsellors) (9%), 9 psychotherapists and psychiatrists (4%), 5 clinical psychologists (2%), 4 managers (2%), 3 general practitioners with a particular interest in counselling patients with cancer in their practices or hospices (1%), and 3 hospital chaplains (1%). Additional professions each representing less than 1% of the total accounted for a further 17 respondents. Three respondents omitted to indicate a current job title.

Workplace

Almost two thirds of the sample (62%) were working currently in a hospital. A further 16% were community based, with smaller numbers working in hospices (6%), voluntary centres (6%), general practices or health centres (2%). Only 2% were engaged in a private capacity. A sizeable proportion (15%) had been in post less than a year. Over half (57%) had been employed for between one and five years and over a quarter (28%) for more than five years.

Training and Qualifications

Only a minority of respondents (18.5%) had any kind of formal qualification in counselling (certificate—11%, diploma—7%, or degree—0.5%). A further 3% had qualifications in clinical psychology or psychotherapy, 2% were qualified psychiatrists, 2% had a Registered Mental Nurse (RMN) qualification and 14% had obtained a Certificate of Qualification in Social Work (CQSW) or equivalent qualification. A majority (77%) had attended some type of training course in counselling and 75% of these were prepared to recommend one or more of the courses which they had attended as helpful.

NHS in-service training courses received only two endorsements and were generally regarded as inadequate by participants.

Impact of Training

Several differences emerged between those counsellors who had attended any training courses in counselling and those who had not. "Trained" counsellors were more likely to have been in post longer ($p < 0.04$) and be funded from sources other than the NHS or charity ($p < 0.075$). They tended to work in a voluntary setting rather than a hospital, hospice or community setting ($p < 0.075$), and experienced more personal benefit from their work ($p < 0.075$). They were more likely to receive support from a colleague ($p = 0.051$) or a therapist ($p = 0.0052$) and to wish to be put in touch with other oncology counsellors ($p < 0.03$).

Funding

The largest single source of funding for respondents' posts originated from charitable sources (40%). Purely NHS funded posts accounted for a slightly lower proportion (38%). Joint NHS/charity funded posts accounted for only 5%. Further analysis indicated a relationship between respondent's salary scale and the source of funding for the post (*Table 1*).

Table 1 Relationship between salary scale and source of funding

	Salary[a]		
	£0–£10,999	*£11,000–£16,999*	*£17,000+*
Source			
National Health Service	2	47	14
Charity	7	56	6
Other	4	12	1

$x_2 = 12.139$; df $= 4$ $p < 0.025$.

[a] Salary scale grouped into categories to ensure at least 20% of expected frequencies greater than five.

The table denotes a greater tendency for the range of higher salaried posts to be NHS funded (reflecting the recent pay awards to nurses) and for the range of lower salaried posts to be funded from charitable sources.

In addition, results indicated that those counsellors who were currently participating in a research project were more likely to be funded from charitable sources ($p < 0.025$) than from the NHS.

Conditions of Work

Counselling duties. As can be seen from *Table 2*, over half of the respondents (50.1%) spent more than 40% of their time actively engaged in what they described as counselling as opposed to teaching, research, nursing or other duties.

There was considerable variability in the number of people currently being seen for counselling. Fourteen respondents (6.4%) were seeing over 40 patients at the time of sending in the questionnaire, whilst 44.2% were seeing fewer than 11 clients, almost a third (32.7%) had caseloads of between 11 and 20, and 12.9% between 21 and 40.

The number of counselling sessions given to patients also differed widely between respondents. A small proportion of counsellors (3%) saw patients for only one session. More typically between two and five sessions was the average given by most counsellors (38%). A quarter (25%) gave between six and ten sessions on average and over a fifth (24%) stated that they would usually provide more than ten sessions per patient.

The counselling sessions themselves lasted for between 15 and 30 minutes according to 43% of the respondents. Session lengths of between 30 minutes and an hour were cited by (37%). Counselling periods averaging more extreme lengths of time than these (less than 15 minutes 3%, more than an hour 11%) were infrequent.

Table 2 Estimated proportion of week spent counselling

Proportion	*Number*	*Percentage*
0–20%	36	16.6%
21–40%	68	31.3%
41–60%	68	31.3%
61–80%	31	14.3%
81–100%	10	4.6%

Counselling models and assessments. Fewer than half the sample (43%) claimed to use a particular counselling scheme or model in their work. The most frequently used single model was Rogerian (7%) followed by unspecified psychodynamic models (4%). Many of the sample (19%) claimed to be eclectic, employing ideas drawn from several different therapeutic models. Formal assessment of patients' psychological status was only ever carried out by 34% of the respondents, usually as part of a research project.

Expressed goals of counsellors. Respondents were asked an open-ended question regarding the goals of counselling—"What do you see as the goals of your work?" Detailed analysis of the replies have been described elsewhere (Roberts and Fallowfield 1990), but in general goals could be divided into five basic categories:

1. *Orientated to service provision* such as "managing a co-ordinated multidisciplinary team".
2. *Orientated to empowering the person*, e.g. "to help them (patients) where possible to achieve any goals they might have and to die where, when and with whom they would like".
3. *Orientated to patients responding as staff wish*, e.g. "encouraging families to *normalise* attitudes to the ill child".
4. *Orientated to research*, e.g. "to finish research projects that I feel will be useful for patients and staff".
5. Other miscellaneous goals.

Counsellors with a formal counselling/psychotherapy qualification were more likely to express goals connected with empowering the patient than those counsellors who lacked qualifications and who tended to express goals orientated to service provision more frequently ($p < 0.05$).

Patients seen. The patients seen by the counsellors came from a variety of different "cancer populations" and the majority of counsellors saw mixed groups of oncology patients (67%). Patients with breast cancer comprised the largest single group of cancers seen (59%), together with those with colorectal cancer (37%). This is probably a reflection of the increasing number of posts in hospitals for breast care specialist nurses who fulfill a counselling role as a major component of their work.

Counselling situation. Patients were more likely to be seen on the ward (75%) than in either their own home (70%) or a private office (68%). This probably reflects the high proportion of hospital based employees in the sample. It does however suggest that a high proportion of counselling interviews may take place in situations where confidentiality and privacy are not all they could be.

Frequency of counselling. Differences emerged in the frequency with which in-patients and out-patients were seen. Half (50%) saw in-patients more than once a week. In comparison only 16% of outpatients were seen more than once a week. Similarly only 6% of counsellors saw in-patients once a month or less, compared with 18% for out-patients. The actual frequencies with which patients were seen was determined solely by the counsellors themselves in 36% of the respondents. One in ten counsellors indicated that this decision lay with their patients. Another 8% indicated that the decision was neither the patient's nor their own and more likely to be determined by organisational factors and practices.

Referrals. The initial request for the counsellor to see the patient was usually taken jointly by the patient and the referring agency (80%).

The largest source of referral for counsellors was from hospital medical staff (84%) followed by nursing staff (76%) and then GPs (54%). A variety of other non-specified sources accounted for referrals to 57% of the respondents.

A substantial number of respondents (77%) had on occasions referred on patients with severe problems to another health professional. Of these instances, liaison psychiatrists were the most frequently referred to group (52%), closely followed by clinical psychologists (43%) and then social workers (34%).

Supervision and responsibility. An alarming number of respondents (36%) stated that they were supervised by no-one. Where supervision was available, this was more likely to be given by a senior nurse (20%). Supervision was provided by psychiatrists in only (7%) of our sample.

The picture regarding the people to whom the counsellors were responsible was marginally more encouraging. Responsibility was more likely to be to a senior nurse (43%) than to either surgeons (3%), psychiatrists (2%), or radiotherapists (1%). Counsellors considered themselves responsible to no-one in 11% of cases.

Available support. A substantial number of respondents who returned questionnaires (39%) felt that they provided the only source of counselling for their patients. Where there were other means of available support this was more likely to come from social workers (55%), than from clinical psychologists (28%), liaison psychiatrists (25%) or volunteer helpers (24%). (All figures above refer to percentages of those to whom other sources of support were available.) Most respondents considered the work done by these other sources of support quite favourably. Over a fifth (21%) indicated that they were *always* a help in managing a patient's problems, 60% that they were usually so. Whilst it is encouraging that over 80% indicate that available support is at least usually helpful, for almost a fifth of our respondents (19%) help was only seen as being occasionally of use. This must be viewed with some disquiet.

Regarding emotional support for the respondents, a high percentage (86%) indicated that they received this. This was seen as coming predominantly from colleagues (82% of those receiving any type of support—71% of whole sample). Thirty percent of respondents were supported by friends, with a similar figure for therapists (35% of those receiving any emotional support).

Table 3 Difficulties hindering work of respondents

Source	*Number*	*% Sample*	*% of those stating any difficulty*
Time	40	18	30
Lack of resources	31	14	24
Workload	30	14	23
Lack of support	19	9	14
Lack of understanding of role	19	9	14
Obstruction from professionals	16	7	12
Lack of training	9	4	7
Too few referrals	3	1	2
Others	36	17	27

Difficulties. Those completing the questionnaire were asked to state whether any difficulties were hindering their work. A majority answered in the affirmative (61%) and *Table 3* describes the main sources of concern.

Time, resources and workload were the most frequently cited difficulties. Some counsellors were troubled by a lack of understanding by others of their role and 12% experienced obstruction from other professionals. There was a greater tendency for respondents to our survey to feel that their role was understood better by their patients (89%) than by other professionals (73%). This was highly statistically significant ($p < 0.0005$).

DISCUSSION

The data which has been presented suggests that little over a quarter of respondents (25%) to this questionnaire have any recognised formal qualifications in counselling, or psychotherapy. This includes those clinical psychologists and psychiatrists who replied to the questionnaire. If one assumes that counselling forms a necessary aspect of social work training, then including the 14% of social workers who responded increases this figure to 40%. Although it may well be true that many unqualified, untrained or minimally trained people can offer useful counselling because of their good basic communication skills, genuineness and commitment to others, it is not universally true that anyone motivated enough can counsel without training. A paucity of training and inadequate supervision, in conjunction with the finding that barely a quarter of our respondents even belonged to any professional counselling organisation, presents a worrying picture of the degree to which workers actively involved in providing psychological care for their patients are sufficiently skilled to do so. Moreover, very few of the respondents gave implicit recognition of this in highlighting lack of training (7%) and support (14%) as difficulties hindering the execution of their work.

The above state of affairs is a reflection of the position which counselling occupies in the total system of patient care delivery and our results suggest a consistent picture of counsellors who are often overworked, undertrained, under-resourced and insufficiently supervised. Their role appears to be understood better by their patients than by their fellow professionals, who in turn are perceived by a number of respondents as being obstructive. Some of these conclusions are supported by Breakwell and Alexander-Dann's (1989) survey of District Health Authorities in the United Kingdom (DHA's). They found for instance that DHA's required no professional grouping other than clinical psychologists to have any qualifications in counselling prior to employment. They also found that in-service training courses provided for staff were invariably short (2 day), a view echoed by many of our respondents. In this context it is of interest to note that of those counselling courses which our respondents were prepared to recommend only two recommendations were received for NHS in-service courses from a total of 137 given. One respondent summed up the view of many: “Courses run by the NHS are not long enough or sufficiently in-depth to recommend.” It is a testament to the people involved in our survey that in the face of the range of difficulties they experience, so many (70%) nevertheless derive much personal benefit from their work.

The authors believe that the present study also draws attention to a number of factors that contribute to the methodological difficulties of appraising counselling interventions, but which are not usually controlled for or considered. For instance, not only is it essential that counsellors be schooled in the same method of counselling, they also need to be of similar levels of skill and experience in applying what they know. Less than half of the counsellors who responded to the survey claimed to use any theoretical model. This, together with the finding that many entertained contrary and conflicting goals in their work, may contribute to the lack of data showing any clear efficacy of counselling amongst patients with cancer. Some counsellors for example felt that empowerment and normalisation were *their* (i.e. the counsellors') goals for patients. This often meant encouraging patients to adopt a "fighting spirit" or facing death "bravely" or responding to life as "normal." Such stereotypes of "good" adjustment to cancer can impose an immense burden on already psychologically compromised individuals.

In our view, it is also of importance that counsellors be matched for the levels of support that they receive in the course of carrying out their work. This is not likely to happen until other professionals working alongside counsellors recognise the necessity for and benefits of counselling supervision. It was clear from responses to our questionnaires that many respondents did not understand the concept of supervision in a counselling context, whereby the supervisor can help evaluate the counsellors' efficacy with patients and offer crucial support. Brightman (1984) sees the principal functions of supervision as building self-confidence in the counsellor and alleviating such things as demoralisation and helplessness. These emotional problems are features of the so called burnout syndrome described by Maslach and Jackson (1981). As emotional burnout is a common phenomenon amongst oncology staff, the lack of appreciation of the need for personal support and supervision is alarming.

It is perhaps worrying that so few of the counsellors' patients were either self-referred or had any say in determining the frequency of meetings. One would expect this to affect levels of actual and perceived control of the counselling process in the patients—to the detriment of counselling efficacy. The role of the patient in the counselling process has been a relatively neglected factor to date, in attempts to elucidate the successful ingredients for psychotherapeutic change. Some authors (Spiegel *et al.*, 1981, for example) have construed the patient as an essentially passive recipient of counselling. Others, however, (Jackins, 1988, for example) have viewed the counselling relationship as a partnership, with each role that of counsellor and patient—carrying with it a different set of responsibilities, which, if working in unison, can maximise the healing resulting from the counselling process. The caseloads being carried by many respondents were so high as to make anything other than "crisis" counselling impossible. Few oncology counsellors in our survey were able to offer prophylactic counselling to prevent the development of more serious psychological distress, which previous studies in women with breast cancer have shown to be unremitting without help (Maguire, 1985; Fallowfield *et al.*, 1990). We believe that results from this survey highlight important factors in the organisation of counselling which work against therapeutic change.

CONCLUSIONS

Although evidence for the efficacy of counselling patients with cancer is still slender, it seems likely that consumer demand and the judgement of oncologists that counselling helps will ensure that posts for oncology counsellors will continue to be created. It is important that these often well motivated counsellors are given appropriate training to enable them to offer appropriate help to their patients. Too often, enthusiasm, a sympathetic attitude and experience in working with patients who have cancer are seen as suitable criteria for appointment. Furthermore, the professional skills that counselling demands, which protect the patient from poor counselling and the counsellor from such pitfalls as emotional burnout, cannot be acquired from a course lasting only a few days. There is some evidence to suggest that a limited period of training nurses in communication skills for example with little supervision, assessment and evaluation, may be damaging (Fielding and Llewelyn, 1987) and the same seems likely to be true of counselling. We would argue for urgent consideration to be given to improving both the training and the working conditions of cancer counsellors in the United Kingdom and in other countries where oncology counselling is being developed.

One problem which also needs addressing is the provision of a central register of oncology counsellors, so that voluntary groups, charities, health professionals and other counsellors know to whom they can refer patients requesting help. As part of our contribution to this, we have compiled a directory of oncology counsellors from those respondents to the survey (72%) who indicated a wish to be included. We hope this will go some way to meet the needs of those who want to contact an oncology counsellor, but who currently have no means of acquiring such information. Secondly, we hope it will provide further means by which existing oncology counsellors can be easily put in contact with one another to arrange mutual support and supervision.

Clinicians who value the presence of an oncology counsellor in their departments need to ensure that prospective candidates for the post hold suitable qualifications or attend recognised accredited courses. The British Association for Counselling can provide information concerning the suitability of various courses available for the training of counsellors. They should also ensure that the counsellors have appropriate support and supervision, if the psychological needs of patients with cancer are to be addressed properly.

Oncology counsellors fulfill a vital and demanding role which cannot be effectively managed without considerable training, experience and support. Counsellors who are not given the opportunity to obtain supervision or to attend workshops and courses designed to maintain the skills and personal growth required, are at risk of developing the very problems which they may be attempting to ameliorate in others.

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