СЛУЖБА СОЦИАЛЬНО-ПСИХОЛОГИЧЕСКОЙ ПОДДЕРЖКИ ДЛЯ ОНКОЛОГИЧЕСКИХ БОЛЬНЫХ И ИХ СЕМЕЙ: ПРОБЛЕМЫ, ВЫЗОВЫ И ВОЗМОЖНОСТИ

PSYCHOSOCIAL SUPPORT SERVICES FOR PATIENTS WITH CANCER AND THEIR FAMILIES:
PROBLEMS, CHALLENGES AND OPPORTUNITIES

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Аннотация:

Несмотря на значительные инвестиции в организацию служб социально-психологической поддержки, распространенность стресса и психологических проблем среди онкологических больных остается неизменно высокой. Тем не менее, есть основания для оптимизма. Наши исследования убедительно свидетельствуют о том, что разработанная нами интегративная служба способна предотвращать значительный стресс и психологические нарушения. Наши исследования также показывают, что в среднем психическое здоровье пациентов, обращающихся к услугам и участвующих в рандомизированных контролируемых исследованиях, становится лучше, чем в сопоставимой выборке людей, не болеющих раком. Наконец, в отличие от других услуг, к которым обращаются преимущественно женщины среднего класса с раком груди, наша интегративная служба используется почти в равных количествах мужчинами и женщинами из всех социально-экономических слоев и со всеми видами рака.

Ключевые слова:

рак, реабилитация, социально-психологическая поддержка, семья.

Abstract:

Despite considerable investment in psychosocial support services, the prevalence of distress and psychological morbidity in patients with cancer remains stubbornly high. However, there are grounds for optimism. There is substantial evidence from our studies that the integrated service that we developed prevents a considerable amount of distress and psychological morbidity. Our studies also show that, on average, the mental health of patients accessing the service and participating in randomised controlled trials becomes better than that of comparable individuals in the community who do not have cancer. Finally, unlike other services which are accessed predominantly by middle class women with breast cancer, our integrated service is used in almost equal numbers by men and women, from all types of socio-economic backgrounds, and with the full range of cancers.

Key words:

cancer, rehabilitation, psychosocial support, family.

Cancer is the second leading cause of death globally, accounting for an estimated 9.6 million deaths, or one in six deaths [1]. However, there are large national differences. For example, cancer is the most common cause of death in the United Kingdom, whereas in Russia

cardiovascular disease accounts for more than three times as many deaths as cancer [2].

For the last 40 years or so, it has been widely recognised that the diagnosis and treatment of cancer can be very stressful. High levels of psychological and psychiatric morbidity have been widely reported throughout the world. In a classic early study of a mixed group of 215 patients in the United States, the point prevalence of psychiatric disorder (excluding personality disorder) was as high as 44% [3]. More recently, a meta-analysis of 70 studies using standardized criteria in oncological and haematological settings across 14 countries found the prevalence of major depression was 15%; minor depression was 19%; adjustment disorder was 19%; anxiety was 10%, and dysthymia was 3%. However, multiple diagnoses were common, and the overall prevalence of any mood disorder, including anxiety, was 38% [4]. The frequency, magnitude and nature of the problems are related to the specific type of cancer, prognosis and treatment, as well as the availability of support and information, unresolved concerns, age, sex, previous history of psychiatric disorder, and personality. Common problems include anxiety, depression, fatigue, body image problems, sexual problems and fear of recurrence (the so-called Damocles's syndrome). It is clear that despite considerable investment in psychosocial services in many parts of the world, morbidity remains stubbornly high.

My own interest in psychosocial aspects of cancer began in the early 1980s when haematologists discovered that by using high dose, combination chemotherapy the prognosis of Hodgkin's Disease, especially in the earlier stages, could be dramatically improved. However, the treatment could have a number of severe side effects, including nausea and vomiting which, in some cases, could be so severe that the patient would refuse further treatment.

The first patient I saw was a young woman with potentially curable Hodgkin's Disease. She had received four of six cycles of combination chemotherapy and, despite the use of the best available antiemetic medication, she was refusing to continue. She had reached the point where not only did she vomit following the chemotherapy infusion, she would vomit in the clinic before chemotherapy (a classically conditioned response). What she described as the 'clinic smell' would intensify her nausea. In addition, she was anxious and irritable, and had trouble sleeping the night before chemotherapy.

I saw her for four sessions before her next cycle of chemotherapy the following week. To try to help her, I developed a novel treatment called nausea management training. Having learned cue-controlled relaxation by means of a combination of live training and an audio recording for home practice, the patient was hypnotised. A feeling of nausea was produced by asking her to recall her previous visit to the clinic or by holding an alcohol wipe close to her nose (this resembled the clinic smell which intensified her nausea). Once the intensity of nausea reached about 7 on a 10-point scale, she would signal this by raising a finger (ideomotor signalling). Then, she was asked to put her hand on her abdomen and gently to massage away the feeling by using relaxation: direct hypnotic suggestions of feeling refreshed and more in control of the feeling were given during this process. Once the nausea had reduced to about zero, she indicated this by raising a finger. This procedure was repeated several times during the sessions. Suggestions of being more able to cope generally with the cancer and its treatment were also given to enhance feelings of self-efficacy. She slept well the night before the next cycle of chemotherapy and experienced no nausea or vomiting before or after chemotherapy.

Two booster sessions were given, and she completed the full course of chemotherapy without undue distress. She was never nauseous or sick again.

Encouraged by these results, we treated with some success a series of 14 patients all of whom had severe chemotherapy side effects [5]. Subsequently, we carried out a randomised controlled trial (RCT) with 63 patients. They all received antiemetic medication throughout the study. Patients were randomised to treatment as usual, relaxation therapy, or relaxation therapy plus nausea management training. Patients randomised to relaxation therapy, or relaxation therapy plus hypnotherapy did not receive the intervention until after the third cycle some 12 weeks later. These studies confirmed that the treatment was beneficial in terms of reducing nausea and vomiting and improving quality of life during treatment. However, the RCT taught us another important lesson. The prevalence of nausea and vomiting at cycle three was only a small fraction of what would have been expected on the basis of our previous experience in the clinic as well as from the published literature. In other words, something about taking part in this RCT appeared to have prevented a considerable amount of nausea and vomiting. We suspected that this might have been because our research fellow made contact with the participants within 24 hours of the diagnosis, providing them with tailored information and ongoing support, and the opportunity to participate in a research study [6].

The possibility that information and support might be important in facilitating coping was supported by the results of one of our next studies. One hundred and seventeen women attending a gynaecological oncology follow-up clinic completed several scales, including the Hospital Anxiety and Depression scale (HADS). Women who were anxious, depressed, or anxious and depressed, at follow-up were more critical of doctor-patient interaction, particularly regarding the amount of information given. Although 47% of the women reported being too shocked to take in details at the time the diagnosis was confirmed, only 3% felt that they had been given too much information at that time and 23% would have preferred more information [7].

Informed by these findings, and in order to minimise distress and to facilitate our research studies, we set up the Aberdeen Behavioural Oncology Unit. The idea was to provide an open access service where patients and their relatives could attend at any time for tailored information and support, and to discuss any cancer-related concern in an informal and relaxing atmosphere. No appointment was necessary, and the kettle was always on. The Unit was located in the Professorial Surgical Unit and chemotherapy was administered in the Unit under the supervision of a consultant medical oncologist. As far as the patients were concerned, therefore, support was an integral and integrated part of their medical and surgical treatment. The Unit was staffed by a clinical psychologist, a junior physician (who administered the chemotherapy), a specialist nurse and a research assistant. Our members of staff were trained to elicit concerns, to assess any clinically significant depression or anxiety and to respond appropriately to their findings.

One of the first studies that we carried out in the Unit was an RCT of 96 patients with locally advanced breast cancer [8]. We wished to find out if our patients could cope better with the diagnosis and treatment if they learned progressive muscular relaxation, cue-controlled relaxation and guided imagery. Within a week of being diagnosed, women were randomized

to a control condition (our standard care in the Behavioural Oncology Unit) or to the experimental condition (our standard care plus relaxation training and imagery). Psychometric tests to evaluate mood and quality of life were carried out before each of the six cycles of chemotherapy and 3 weeks after cycle 6: tests of personality and coping were carried out before cycles one and six.

As hypothesized, patients in the experimental group were more relaxed and easier going during the study and their quality of life was better. The intervention also reduced emotional suppression. The incidence of clinically significant mood disturbance did not differ significantly between the experimental and control groups, and the incidence in the two groups was very low.

Following diagnosis, before the start of chemotherapy, the point prevalence of anxiety in all 96 patients as assessed by the HADS-A (>10) was 21% which fell to 5% pre-surgery and to only 2% post radiotherapy (37 weeks post diagnosis). To put this in context, we had recently found using the HADS in the same region of Scotland that the prevalence of clinically significant anxiety in female police officers was 24% and in the wives of police officers it was 19% [9]. For depression (HADS-D >7), the point prevalence before chemotherapy was 3%, pre-surgery 4% and post radiotherapy 0%. Using the same cut-offs for the HADS, the prevalence in female police officers was 6% and in wives of police officers it was 10%. Also, to help to put these figures in context, a normative study of HADS scores in a community-based study of 3,491 women in the North of England using the same cut-offs found a point prevalence of 19% for anxiety and 17% for depression [10]. Furthermore, standardised clinical interviews confirmed a very low rate of psychiatric morbidity using DSM-III criteria [11]. In other words, it appeared that compared with women who did not have cancer, the mental health of the patients in this study was similar following the diagnosis and, remarkably, actually improved significantly during the study.

These findings, therefore, supported our hypothesis that, by providing integrated information and support, considerable distress and morbidity could be prevented. A subsequent RCT to evaluate the effects of sequential docetaxel chemotherapy on 162 patients with large or locally advanced breast cancer was carried out within the auspices of the Unit. Again, a very low incidence of distress and psychological morbidity was found [12,13].

In 1999, the opportunity arose to develop a larger and more ambitious support service for patients with cancer in another part of the UK, and this allowed us to see if the Aberdeen results could be replicated. The Kingston upon Hull Oncology Health Service (OHS) is based on the Aberdeen findings and model, and it is funded by the National Health Service. A full description of the OHS, together with the rationale, have been previously published [14]. In brief, it aims to provide information, support and evidence-based interventions to prevent and treat distress. In addition, patients can have access to self-help methods such as relaxation and imagery and can access various evidence-based complementary therapies (reflexology and massage). The OHS is fully integrated physically, functionally, financially and managerially with other parts of local NHS oncology provision. Patients and their families can access the Oncology Health Service either by traditional referral or via an open access drop-in centre which is staffed by Specialist Nurses. If they prefer, they can also access the service by telephone.

Because the service is integrated with all other aspects of the oncology services, and is based in the oncology hospital, staff can access medical notes to obtain up to date information about treatment and prognosis. Importantly, medical concerns can be resolved by liaising immediately with the relevant members of the clinical team who are available on site. Since it is staffed by a specially trained and supervised multi-disciplinary team comprising Specialist Nurses and Clinical Health Psychologists, any significant distress which does arise can be identified and treated efficiently without the requirement to refer patients to tertiary services outside of the Cancer Centre. A range of evidence-based interventions is offered to help with clinically significant anxiety and depression, sexual difficulties, fatigue, adjustment problems, phobic difficulties that are interfering with treatment, and other cancer-related distress.

Nine months after the service was established, a consecutive series of 51 patients and 38 relatives who had visited the Centre at least once completed anonymously a Satisfaction Questionnaire. They agreed unanimously that the Oncology Health Centre provided a unique dimension of care; that staff understood and responded helpfully to their concerns; that they had received a warm welcome, and that they had found it useful to talk with the nurses in the Centre. A survey of referrers also indicated a very high level of satisfaction with the service offered. A further audit in 2009 showed that 2,700 new patients per year were accessing the service, and 315 patients and almost as many relatives were attending each week.

Using this new infrastructure for our research, we carried out a number of RCTs. In one study, we evaluated the effects of foot reflexology on mood, coping and quality of life in one hundred and eighty-three women with early breast cancer [15]. These patients were randomised 6 weeks post-breast surgery to support within the Oncology Health Centre ('treatment as usual' control), support plus reflexology, or support plus scalp massage (control for physical and social contact). Reflexology and massage comprised eight sessions at weekly intervals. Both reflexology and massage had beneficial effects, but there were no significant between group differences in HADS anxiety and depression. As in the previous RCTs, the prevalence of clinically significant anxiety and depression was very low in all groups, including support alone. In the support alone group, 24 weeks post-surgery, only 2% qualified for a DSM diagnosis. This compares extremely favourably, for example, with a prevalence of 50% for anxiety and 37% for depression reported by Hall et al. (2002) using the Present State Examination in their study of patients with early breast cancer [16].

A further study of 151 patients with newly diagnosed colorectal cancer (Duke's stage B, C or D) took part in a pragmatic randomised trial [17]. They were randomised remotely to one of four interventions: support in the Oncology Health Centre, support plus relaxation, support plus guided imagery, or support plus relaxation plus guided imagery. Once again, the prevalence of distress throughout the study was much lower than that reported in other clinical trials and comparable populations. In the support alone group, at week 42 (by which time all patients had completed medical, surgical and radiation treatments), only 6% qualified for a DSM diagnosis compared with a point prevalence of 32% for patients with colorectal cancer reported by Zabora et al. (2002) in their international review.

These studies in Aberdeen and Kingston upon Hull strongly suggest, therefore, that this

fully integrated, open access model of care prevents a considerable amount of psychological and psychiatric morbidity. However, there is one further major advantage and that is equity of use. There is widespread agreement that support services should be equitable in the sense that they are available to anyone who wishes to access them. However, the problem is that equity of access does not necessarily translate into equity of use. Despite having equity of access, studies of support services in the UK and elsewhere have consistently found that those attending are predominantly white, middle class women with breast cancer. Women with other types of cancer, and men, are conspicuous by their relative absence. One review found that only 23-29% of patients accessing support services were male [18]. Others have noted that psychosocial support services are accessed predominantly by white, middle class women with breast cancer [19].

To assess equity of use in the OHS, a cross-sectional study of all patients with cancer accessing the service during a five-day period was carried out [20]. One hundred and forty-five patients attended. Forty-four percent were male, and the types of cancer were broadly in the proportions expected on the basis of population prevalence (breast cancer 22%, colorectal cancer 21%, lung cancer 16%). Sixty six percent came from the three most deprived quintiles of the Townsend Deprivation Index which broadly reflects the local demographics. Our model of support, therefore, delivers a high level of equity, not just in terms of access, but more importantly in terms of actual usage by men and women with all types of cancer.

In conclusion, in Europe, the USA, Australia and elsewhere, despite considerable investment in psychosocial support services, the prevalence of distress and psychological morbidity remains stubbornly high. However, there are grounds for optimism. The integrated service that we developed, initially in Aberdeen and subsequently on a larger scale in Kingston upon Hull, appears to prevent a considerable amount of distress and psychological morbidity. Indeed, we have evidence that on average the mental health of patients using these services actually becomes better than that of community populations who do not have cancer, perhaps indicating post traumatic growth. Moreover, unlike other approaches which are accessed predominantly by middle class women with breast cancer, our integrated service is used in almost equal numbers by men and women, from all types of socio-economic backgrounds and with the full range of cancers.

It is well known that other illnesses, for example neurological disorders and cardiovascular disease, are also associated with high levels of distress. It would be interesting to see if a service along similar lines for these patients would prove equally popular and effective in minimising morbidity and promoting positive adaptation.

As the famous 18th century polymath Benjamin Franklin once said in another context, 'An ounce of prevention is worth a pound of cure'.

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