ABSTRACT

Established in 1993 after a 2-year consultation between professionals and cancer patients, the Lynda Jackson Macmillan Centre (LJMC) has been a catalyst for change in the United Kingdom. The Centre began with a small core staff in a purpose-built building next to a cancer centre, networking with outreach workers in 12 surrounding hospitals, with a mission to improve information, communication, and support for cancer patients. Since 1996, the LJMC model has been adopted and developed by the charity Macmillan Cancer Support and has been spread to more than 60 units across the United Kingdom and Australia.

Introducing complementary therapies (CAMs) to a cancer centre was a particular early challenge. Establishing a shared understanding of the role of complementary therapies and developing nationally accredited written information about them, credible recruitment and governance procedures for therapy practitioners, agreed outcome measures, and peer-reviewed evaluation and research have all been important in engaging cancer physicians and managers; however, charitable funding is still required to support free access to most complementary therapies.

An integrated supportive care service for cancer patients begins with a shift in the culture of cancer treatment organizations, moving from a professional-centred to a patient-centred agenda. Real reach and impact requires “new” ideas and services to be integrated into the routine practice of the cancer care delivery organizations. A key lesson learned over the last 15 years is that an integrated support centre must continually adapt to be viable. Sustaining meaningful user guidance is a particular challenge. Support for self-management and the testing and development of CAM services are growing parts of the portfolio.

KEY WORDS

Cancer support, Macmillan, CAM, complementary, patient-centered, survivorship

1. BACKGROUND

Mount Vernon Cancer Centre serves a population of two million. Annually, 5000 new cancer patients are referred to 25 oncology consultants, with oncologists visiting 12 district general hospitals and liaising with more than 100 surgeons and physicians and with 10,000 primary care physicians and community nurses.

In 1986, a survey of cancer patients treated at the centre identified information, communication, and support as key unmet needs. A 2-year consultation with professionals and users to guide the choice of services and to develop effective ways of working together led to the charity Macmillan Cancer Support offering a grant for a purpose-built facility next to the cancer centre, together with 2 years of funding for 3 core staff. Strong local voluntary initiatives provided the rest of the basic funding and remained a driving force for the centre’s development. The centre began with a medical director, a senior manager/counsellor, a volunteer information coordinator, a complementary therapy coordinator, and a data manager/researcher, who were joined by a team of volunteer support workers, complementary therapists, and counsellors. Staff were initially charitably funded, but follow-up funding came from block cancer contracts between commissioners and the cancer centre. Table 1 and Figure 1 illustrate the service model.

Core functions of the centre in 1993 included

- supportive listening,
- information and signposting,
- complementary and psychological therapies,

TABLE 1  The approach—for example, to complementary and alternative medicine (CAM)

1. Identify CAM approaches currently used.
2. Identify, screen and train therapists.
3. Develop a shared language (written).
4. Conduct pilot studies—specific effects.
5. Measure qualitative factors—non-specific effects.
6. Test a service, and conduct randomized controlled trials.

E.J. Maher
education and training (in particular communication skills), and
patient-centred research.

2. A MODEL OF CONSUMER INVOLVEMENT

The philosophy underpinning the centre was the involvement of patients as consumers 2–4:

- Establishment of a network of cancer support groups representing consumer views
- Consultation of the network through a representative committee that meets regularly to discuss issues and to prioritize
- Consultation on specific issues both with professional staff (through semi-structured interviews) and with patients (through focus groups and interviews)
- Establishment of the ground rules of patient and professional committees, including advocacy training (developing into the Cancer Voices training)
- Delivery of knowledge products—for example, recommendations, information, and guidelines to support changes in practice 5

The consumer model was adapted and developed into the English National Cancer Voices Programme and National Network Partnership Groups 6.

Between 1995 and 2002, the LJMC patient involvement research unit drove the research priorities of LJMC, starting with a “communication of bad news” project, an exploration of self-triggered follow-up after cancer treatment 7, and management of hormonal side effects and of late effects of cancer treatment 8. The projects stimulated development of implementable guidelines 9; written information; a communication skills training program (delivering training to more than 2000 different health professionals, from secretaries to senior physicians and surgeons); and a user-led Living with Cancer program. It also led to a program of research and development related to complementary and alternative medicine (CAM) interventions to help with the adverse effects of cancer treatment—for example, aromatherapy massage for treatment-related anxiety and auricular acupuncture for menopausal side effects associated with hormone therapy.

2.1 Establishing Need

From the start, the LJMC systematically used patient-reported outcomes—in particular, the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ30), which led to the forging of strong links with the EORTC quality of life group. In the first baseline audit, a consecutive sample of 369 patients attending the cancer centre to begin a course of treatment were given a range of questionnaires, including the Hospital Anxiety and Depression Scale 10 and a research questionnaire examining the use of hospital and community services and satisfaction with information and support during and after cancer treatment 11,12. The study found that

- significant levels of psychological distress were affecting all aspects of quality of life measured by the EORTC QLQ30, and
- problems related to information and support were often more acute after attendance at the Cancer Centre rather than during the treatment.

Familiarizing complementary therapists with multidimensional quality-of-life measures was an important part of developing a shared understanding of outcome.

2.2 Services

2.2.1 The Drop-In Centre

The centre provides a Monday-to-Friday free-access drop-in service, augmented by a telephone help line for cancer patients, their families, and health professionals. At any one time, 1–3 trained volunteers supported by at least 1 health professional welcome patients and provide supportive listening, access to and guidance through information materials and Internet sites, and an assessment of whether other services might be helpful—for example, referral for therapies or open-access services such as Living with Cancer programs and exercise or relaxation classes.

Complementary therapies are delivered by a mixture of trained volunteers and paid staff under an established governance framework (Howells N. Developing a regional network of aromatherapists and reflexologists for cancer patients by identifying and meeting education and training needs. Presented at the British Oncological Association; Manchester, U.K.; September 14–16, 2003). Mentoring and additional psychological services are provided by counselling psychologists and a liaison psychiatrist. All staff (including volunteers) have contracts with the cancer centre, and interactions are logged.

By 1995, just under one quarter of patients attending the cancer centre were using LJMC. Of the first 3500 queries, 60% were handled by a volunteer within 10–30 minutes. A request for “medical information” often masks a wide range of unmet needs, with LJMC
acting as a “safety net” for patients treated at the cancer centre who have not understood information provided by front-line professionals.

2.2.2 Information
Between 1993 and 2002, the development and delivery of information materials was a core service. A classification system was devised based on the information needs of the patients, expressed in lay terms. An accredited information development system and award-winning Web site were established. More than 2000 leaflets and books were made available, including information packs with low-cost downloadable supplements to national information. Insights developed during this period were fed into the English Cancer Plan in 2000. The subsequent development of national information pathways and content has meant that information development is a declining part of the LJMC work; however, bringing patients and professionals together to produce written information and, through that process, to develop a shared understanding, continues to be an important part of the LJMC approach to introducing CAM therapies to the cancer centre. The LJMC has won eight British Medical Association awards for written information, most recently about the use of auricular acupuncture.

2.2.3 Therapeutic Interventions
Patients undergoing treatment are offered therapeutic interventions, including

- counselling,
- psychological therapies based on cognitive behavioural therapy,
- aromatherapy massage,
- acupuncture, and
- reflexology.

These interventions were chosen based on what the patients were already using and had found useful, confirmed by a local audit. National Health Service patients undergoing treatment at the cancer centre receive these interventions free, by referral from either health care professionals or volunteer support workers. Patients who wish to continue the holistic approach after completion of treatment are referred to local community-based counsellors, complementary therapists, and support groups that have been established and given basic training in working with cancer patients (Howells N. Developing a regional network of aromatherapists and reflexologists for cancer patients by identifying and meeting education and training needs. Presented at the British Oncological Association; Manchester, U.K.; September 14–16, 2003).

The need to integrate face-to-face communication, information materials, and psychological therapies was quickly recognized. The cancer centre’s early response to high levels of anxiety in the visiting cancer patients was to appoint a radiographer/counsellor. It became clear, however, that 80% of her initial interviews related to unmet information needs rather than to a need for talk therapy. As routine information provision improved, counselling referrals changed to handle adjustment difficulties, reactive depression and anxiety, and behavioural problems or phobias; brief interventions based on cognitive behavioural therapy replaced longer courses of “talk therapy.”

Complementary therapies were introduced gradually, initially focusing on “touch, talk, and time.” The underpinning philosophy was development of a shared language between patients, therapists, and health professionals, leading to integrated research and development projects. The approach can be illustrated by the introduction of aromatherapy massage. A pilot study of 20 patients, followed by semi-structured interviews and focus groups, established referral criteria, service models, and outcome measures that were meaningful for all stakeholders.

Patients fell into three groups:

- Anxious, but reluctant to consider “talk therapies”
- Difficult side effects associated with treatment
- Terminally ill patients with multiple symptoms

A volunteer therapist ward-based service was established for single treatments for the very ill patients, with courses of 6 treatments established for patients in the other two groups. Early agreed outcome measures included changes in the Physical subscale of the EORTC QLQ30 and in the Hospital Anxiety and Depression Scale before and after therapy. Of 89 patients referred for aromatherapy, 50% reported an improvement in the eight most commonly assessed symptoms. The pilot was sufficient for the cancer centre to accept the aromatherapy massage service, but in addition, a multicentre randomized controlled trial explored the effect of aromatherapy massage on anxiety and demonstrated a clinically important benefit up to 2 weeks after the intervention.

A similar approach linking evaluation, research, and service development has been taken in the introduction of relaxation, reflexology, and auricular acupuncture.

3. CONCLUSIONS

The LJMC has now been established for more than 15 years. Significant improvements have been made in the supportive care of cancer patients, but significant challenges remain, particularly in the field of cancer survivorship, support for self-management, and testing and development of CAM therapies.

4. REFERENCES

1. Maher EJ, Barton L, Ashby J, Dickson R. The role of the palliative care unit in the organisation of services to patients with cancer: a discussion paper based on local attitudes to


Correspondence to: E. Jane Maher, Mount Vernon Cancer Centre, Northwood, Middlesex HA6 2RN U.K. E-mail: jane.maher@mvh-ljmcc.org