Interface Between Research and Practice in Psycho-Oncology

Jessica Corner

From the Centre for Cancer and Palliative Care Studies, Institute of Cancer Research, London

Correspondence to: Professor Jessica Corner, PhD, BSc, RGN, Director and Deputy Dean (Nursing), Centre for Cancer and Palliative Care Studies, Institute of Cancer Research, Royal Marsden NHS Trust, Fulham Road, London SW3 6JJ

Acta Oncologica Vol. 38, No. 6, pp. 703–707, 1999

Examination of the interface between research and practice in any field inevitably raises questions over whether the most important issues are addressed by researchers, or indeed whether the findings of studies have sufficient relevance to practice. As a field of study develops its own research methods and language, a chasm often opens between the producers of research findings and the consumers. Psychosocial oncology is no different. Early work which highlighted the psychosocial impact of a cancer diagnosis, and how health professionals helped or hindered coping with the disease, was ground breaking, and highly relevant to the way cancer services subsequently developed. However, as psychosocial oncology has evolved into an established research discipline, it has become increasingly oriented around measurement (e.g., quality of life, psychopathology, communication skills). The paradox here is that the more reliable psychosocial measures become, the less direct relevance they appear to have for everyday practice in cancer treatment centres. Solutions to this problem could be found through reintegrating psychological and physical aspects of cancer; by changing the orientation of research from measurement of the disruption imposed by cancer and its treatment, to evaluations of more clinically relevant models of care; and by using collaborative models of research in studies in order to promote closer involvement of health professionals and people who have cancer.

Received 17 September 1998
Accepted 21 January 1999

Health policy-makers world-wide are preoccupied with questions concerning clinical effectiveness, costs, the evidence base for healthcare interventions and technologies, and how to deal with the vast and growing mound of studies published each year in medical journals. All of these concerns surround the interface between research and practice, ensuring that best practice is based on evidence.

Those working in psychosocial oncology should also be concerned about the interface between research and practice. In particular we should consider what contribution has been made to the lives of people with cancer and to the practices of the health professionals caring for them by the growing research endeavour within psychosocial oncology. Two questions seem fundamental to this issue:

Are we using the findings from research in psychosocial oncology to inform and improve practice?

Are the research questions that are being posed related to clinically relevant issues?

Psychosocial oncology is concerned with the relationship between cancer and the mind, and has pursued a number of core themes (1):-

- The effects of cancer and its treatment on the emotional state of patients, their families and the staff who care for them.
- The ways in which undesirable emotional reactions in response to a cancer diagnosis can be prevented or treated.
- The possible influence of psychological and social factors on the development of cancer or its rate of growth.
- How to introduce research findings into everyday clinical practice, for example:
- the organization of diagnostic and treatment services from a psychological viewpoint;
- how staff can recognize emotional distress;
- who should provide psychosocial care;
- who would benefit from specialized counselling.

Work in each of these areas has been instrumental in the development of cancer services which not only focus on treatment, but also emphasize the need for a diagnosis to be told sensitively and carefully; to make available a range of support services; and to acknowledge the impact cancer has on patients, families and friends. Psychosocial oncology has made a very substantial contribution to our

ISSN 0284-186X

understanding of the needs of people with cancer in a range of areas, particularly studies that have developed insights and evidence regarding:

- Recognition of the impact of a cancer diagnosis on individuals, families and friends; but also the importance of open communication about the disease.
- The development of understanding of the processes of adjustment to a diagnosis of cancer, and in undergoing the various forms of treatment for it, and what factors appear to ease or complicate this.
- The incidence and prevalence of psychopathology associated with cancer and cancer treatment.
- Evidence showing the contribution of specialist nurses in identifying people who have adjustment disorders; in offering supportive and informational care at the time of diagnosis and beyond; and ensuring that appropriate psychological and psychiatric treatments are made available to those with difficulties in adjusting to cancer.
- Evidence for the effectiveness of psychological interventions to alleviate emotional distress and psychological morbidity, associated with cancer and cancer treatment.
- The development of measures for the assessment of psychosocial aspects of cancer, and psychosocial outcomes of treatment, in particular measures of quality of life.
- Evidence relating to what constitutes effective, and supportive communication by health professionals with people who have cancer; methods of facilitating people with cancer to participate in decision-making about treatment; and methods of training health professionals in these skills.

Comprehensive and supportive services based on evidence from these studies are, however, not universally available. There remains substantial evidence to suggest that in reality, caring may have changed much less than we imagine. Many of the recommendations emanating from even the best-known studies are still not uniformly part of everyday practice (2). While this is not an uncommon problem in any field of research, the interface between research and practice is frequently the subject of questions over whether researchers address the important issues, or whether the findings of studies have sufficient relevance to practice. As a field of study develops its own research methods and language, the chasm between the producers of research findings and the consumers can become great. There may, however, be some specific reasons for the failure of psychosocial oncology to deliver more. Indeed, there may be a growing, rather than a narrowing gap between research and the realities of practice in this area.

I recently met a new manager of a UK cancer charity, who had just attended a British Psychosocial Oncology Society conference and was shocked to discover that the conference delegates and speakers appeared to be preoccupied by measures and measurements. Every aspect of psychosocial oncology had been reduced, or so it seemed, to a set of scores, or p-values and confidence intervals. It seemed that ‘people’ with cancer were entirely absent from the discussions about the impact of cancer on the mind and the emotions. The research had become entirely divorced from the people being researched. The paradox here is that the more ‘reliable’ psychosocial measures become, and the more refined and sophisticated the ability to capture cancer and its relationship to the mind, the less direct relevance the results from studies using these measures appear to have for practice and ‘people’ in cancer treatment settings. Psychosocial oncology needs to look closely at the main themes and methods that have been adopted, in order to create a more seamless integration between research and practice in psychosocial care and cancer.

QUALITY OF LIFE AND CANCER

Quality of life has been the focus of much research activity in psycho-oncology. The use of quality of life as a concept to represent the range of domains (physical, psychological, social and functional) that may be disrupted by cancer or its treatment, and the development of measures to record these domains has enabled detailed mapping of the consequences of treatment and comparisons between different treatments to be made. International projects to develop measures that can be used across studies and populations, such as the EORTC Scale (3), have been significant achievements. Yet it is these very measures that are the subject of criticism, because they yield data that offer such narrow insights into a complex disease and into life when facing cancer.

The measurement of quality of life, because it has primarily been pursued for the purposes of research, has questionable relevance to practice. Test results using quality of life measures are held by researchers and are therefore remote from both patient and the person providing care; individual scores are not used to improve function or physical symptoms. Since analysis of quality of life data is undertaken as a post hoc exercise, scores derived from patients capture a moment in time for that patient, but these are not scores which any one seeks to alter. Collective data for a cohort of patients are derived, but these results are reserved for publication in medical and research journals. These data are for the use of an audience remote from the treatment setting; they do not feed into care or treatment in the environment from which they were derived in any immediate way. The measures themselves are largely unsuitable for monitoring and improving direct care. They are time-consuming to complete, and difficult to analyse and interpret. Even quality of life researchers themselves, struggle to make sense of complex longitudinal data sets derived from multiple assessments of quality of life.

A 'NORMATIVE' MODEL OF PSYCHOLOGICAL ADJUSTMENT

In investigations of the effect of cancer on the mind, psycho-oncology has adopted a 'normative' model (4). Weisman's (5) seminal work on coping with cancer, for example, has been criticized on two counts: for proposing that there are 'good' and 'bad' ways of coping and for producing overly simplistic lists of 'healthy' coping strategies. These strategies ignore the context beyond cancer and the person, and also assume that individual traits determine healthy adjustment. Society, social and cultural influences on responses to cancer are overlooked. A person is seen either to follow a path towards adjustment, which is psychologically 'healthy', or to maladjustment, when psychological ill health will ensue (6).

Researchers have been preoccupied with identifying the incidence and prevalence of psychological ill health, focusing in particular on 'caseness' in relation to anxiety and depression (7). This has been important since it has served to highlight the deep distress associated with a cancer diagnosis, and therefore the need for services to deal with this level of psychological morbidity. It has unfortunately, at the same time, led to the distress surrounding cancer being defined in very narrow terms. Anxiety or depression does not represent the range of emotional difficulties and distress experienced by people with cancer. This pathologized version of the psychology of cancer neglects the more everyday experiences of people seeking to come to terms with loss and change in their lives as a consequence of illness, and confines the problem to the relatively small number of people who may have psychiatric disorders. There is much discussion and debate going on in psychosocial oncology research circles about the definition of 'caseness' and the sensitivity of various approaches to assessing this concept (8). Much less effort has been directed to ways of dealing with varying levels of distress, or in equipping health carers to deal with this effectively and sensitively; while also differentiating the real 'cases' that warrant specialist psychological or psychiatric intervention.

PSYCHOSOCIAL INTERVENTIONS

A body of research exists which has evaluated a range of psychosocial interventions (9, 10). These include informational or educational care, cognitive-behavioural training, individual psychotherapy or counselling, and group interventions (11). A number of reviews and meta-analyses of data from studies of psychosocial interventions have been undertaken (12). The findings of these studies are equivocal. Not all studies show significant results in favour of the various interventions employed. The reviews appear to conclude that some benefit can be derived from receiving intervention, although effect size appears to be small, and study designs and sample sizes are not adequate to allow more definitive results. Thus after 20 years of research we know that people derive benefit, but not who, or whether intervention should be targeted at those who have significant problems. We also do not know whether particular types of intervention are best suited to particular problems or situations. This work therefore offers very little guidance to service managers or health policy-makers, since no definitive recommendations are available. Given such uncertainty, it is not surprising that only limited resources have been directed towards providing psychological support services.

The problem lies in the sheer difficulty of undertaking research in order to evaluate the effectiveness of psychosocial intervention. Defining the interventions and outcomes that could result from research is an important challenge; to date, these remain crude relative to the complexity of psychological needs and psychotherapeutic care. Much greater resources and effort need to be directed toward these kinds of evaluations if clinically relevant findings are to be delivered.

COMMUNICATION SKILLS AND CANCER

The way in which doctors and nurses communicate about cancer has been the subject of considerable attention. From the earliest studies there has been a preoccupation with whether a diagnosis of cancer should be given, studies concerning the attitudes of doctors and nurses towards 'telling' were undertaken and revealed great reticence about giving full information; subsequently, not doing this was seen as 'poor communication' (13). As the debate surrounding whether to 'tell' subsided, close scrutiny of how 'bad news' should be given began, and the methods by which health professionals could be trained to use these techniques in their encounters with patients were tested in various experiments (14–17). More recently, work has begun on investigating how patients could be involved in decisions about their treatment. This has largely been evaluated in terms of the relationship between involvement in decisions and avoidance of subsequent psychological morbidity (18, 19).

Experiments in communication skills training, using video simulations and role-play, use structured scoring systems of observed communication behaviour to evaluate the use of 'best practice' communication skills. These have demonstrated that relatively short, workshop-type courses can enhance the skills of health professionals, although few studies demonstrate that these skills are maintained at the same level over time (14–16, 20).

At one level, this body of work has been powerful. It is no longer considered acceptable practice to withhold information concerning a diagnosis of cancer; insensitive communication is considered bad practice, and the need for training in communication skills as part of basic medical and nursing training is also accepted. However, there is still plenty of evidence to suggest that even these basic expectations are not fulfilled for patients with cancer (2). The quality of communication is influenced as much by the type of cancer, age, social and educational background, and the prejudices of those providing care, as the inherent skills of health personnel. Doctors, nurses and other health professionals still report enormous stress and difficulty in managing communication in relation to cancer and its treatment, emotions, sexual and intimate concerns, prognosis and dying. These are the very areas that patients complain are being overlooked or handled insensitively. Two decades of communication skills training have brought about important change, but further progress in overcoming barriers to communication is hampered by some limitations inherent in the way research is being conducted.

The notion that communication skills can be defined as observable skills that can be learned takes an overly mechanistic approach, and does not place enough emphasis on the environment and organizational culture in which health professionals develop their clinical personas. Skill in communicating is complex and resists definition and description as an entity in this form. There has also been too great an emphasis on seeing the health professional as the sole determinant of 'quality' communication. This has not sufficiently taken into account environmental and contextual factors that contribute to encounters with people who have cancer, going 'well' or 'badly'. Little attention has been given to the patient/person with cancer, who in many subtle ways influences the form, character and tone of communication. We understand very little about the subtleties of the interplay between the health professional and patient in interactions about cancer, or the skills which facilitate genuinely person-centred communication. Most importantly, and an area where little information exists, there are the organizational and individual support structures that are necessary to facilitate engagement in the emotions and distress of people with cancer and their families, or how this engagement can be sustained over a career of 'bad news' consultations or conversations aimed at facilitating adjustment to the experience of cancer or dying.

Psychosocial oncology is hampered by its origins in 'psychology'. This has too narrowly defined the subject as 'the relationship between cancer and the mind' (op. cit.). Most of the questions that require researching are much more complex; no straightforward relationship exists between cancer as a physical experience and its effects on emotions and feelings. Cancer is an experience of mind and body; more than this, the experience is also influenced by social and organizational cultures, and lay and professional systems of understanding. Research located in the Cartesian empiricist tradition will never permit a full understanding of these various influences, and the gap between researcher and practice, and researchers and consumers of research findings will be perpetuated.

The interface between research and practice may be better served by reorienting research questions and the studies designed to answer them. First, research questions need to be more closely aligned to health service needs (for example, questions which are need driven, explore issues such as workload, efficacy, client satisfaction and cost). Secondly, research and practice need to be brought together and integrated creatively within the study design. This might be more readily achieved if:

- Researchers move away from studies oriented around prospective monitoring of patients, and post hoc analysis of data derived from these studies (as in quality of life studies); to research that has more immediate relevance to, and revolves around intervention for problems that are current.
- Psychological and physical aspects of cancer are reintegrated, rather than seen as separate entities.
- Studies involve closer cooperation and collaboration between researchers, health professionals and people with cancer.
- Research is conducted which is responsive to the needs of health professionals and people with cancer, and is also collaborative, participative and mutually beneficial in an immediate way to researchers and their research subjects (21).
- Research aims to reconstruct cancer services for the benefit of people using them. This should be inherent in the study as it is conducted, and not in what may be recommended for future practice once the study has been completed.

Along with colleagues at the Institute of Cancer Research in London, I have attempted to follow these tenets in a programme of research on nursing intervention for breathlessness in lung cancer. We identified a disadvantaged client group, where there has been insufficient research into the provision of supportive care, and a symptom where current palliative management is recognized to be inadequate. We developed an intervention approach based on non-pharmacological methods, acknowledging fears and what breathlessness can mean in the context of life-threatening illness. At the pilot stage, this work was carried out in an active collaboration with patients. In dialogue with them, whilst conducting a small randomized controlled trial of nursing intervention versus standard care, we learned from the patients about breathlessness and the fears surrounding this problem. We learned about the triggers for this symptom, and together with the patients developed and honed the intervention, demonstrating in a small group of patients ($n = 34$) that significant benefits could accrue (22).

This then needed replication, to determine whether our findings could be translated into practice on a wider scale in other settings. We conducted a multicentre, randomized, controlled trial of nursing intervention for breathlessness. However, it became much more than a trial of a novel intervention. We established this as a collaborative inquiry within a conventional RCT design. On this occasion, specialist nurses became our collaborators, while the patients became their collaborators. We established a supportive framework, where we as the research centre provided training, support and supervision to the nurses both in the intervention and in conducting the research, while also providing the infrastructure for the research (protocols, ethics clearance, independent randomization, data management and analysis) (23). We hosted regular meetings to bring the centres together to discuss progress, difficulties and achievements. We insisted that each centre set up its own internal support structures to sustain the research. Finally, we set up a study to research the researchers (the nurse specialists), so that we could learn from the process of involving nurses in this kind of work. This has not been a post hoc analysis of the interviews conducted with them over the duration of the study. The nurse specialists hold final ownership of their data, and are themselves now developing their own written impressions of some of their experiences. They openly acknowledge that the environment of care has changed as a result of the research, and understand that they have been instrumental in this. They feel a sense of achievement in the process. This research approach has allowed conventional research data and findings to emerge, as well as a process of practice development and change to unfold for nurse collaborators as well as the healthcare settings in which they undertake the work.

CONCLUSION

The interface between research and practice can be chasmic. This need not be the case, but the challenges of developing research which is truly responsive to the needs of people with cancer and the practitioners working with them are considerable. These challenges can only be overcome by coming closer to practice, by seeing practitioners and patients as equals in a mutual project of discovery about how to bring about change. Seen in this light, the future for psychosocial oncology is indeed exciting.

ACKNOWLEDGEMENTS

Grateful acknowledgement is made to Cancer Relief Macmillan for funding the study of nursing intervention for bleaklessness in lung cancer.

REFERENCES

1. Barraclough J. Cancer and emotions: a practical guide to psycho-oncology. 2nd edn. Chichester: John Wiley, 1994.
2. National Cancer Alliance. Patient centred cancer services? What patients say. Oxford: National Cancer Alliance, 1996
3. Aaronson NK, Ahmedzai S, Bergman B, et al. The EORTC QLQ—C30: A quality of life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 1993; 85: 365–76.
4. Benner P, Wrubel J. The primacy of caring: stress and coping in health and illness. Memlo Park, California: Addison Welsley, 1989.
5. Weisman AD. Coping with cancer. New York: McGraw Hill, 1979.
6. Greer S, Silberfarb PM. Psychological concomitants of cancer: current state of research. Psychol Med 1982; 12: 563–637.
7. Maguire P. Psychosocial interventions to reduce affective disorders in cancer patients: research priorities. Psycho-oncol 1995; 4: 113–9.
8. Hopwood P, Howell A, Maguire P. Screening for psychiatric morbidity in patients with advanced breast cancer: validation of two self report questionnaires. Br J Cancer 1991; 64: 353–6.
9. Trjsburg RW, Van Knippenberg FCE, Rijpman SE. Effects of psychological treatment on cancer patients: a critical review of psychosocial interventions in cancer care. Psychosom Med 1992; 54: 489–517.
10. Watson M. Psychosocial intervention with cancer patients: a review. Psychol Med 1983; 13: 839–46.
11. Fawzy FI, Fawzy NW, Arndt LA, Pasnau RO. Critical review of psychosocial intervention with adult cancer patients: a meta-analysis of randomised experiments. Health Psychology. 1995; 52: 100–13.
12. Meyer T J, Mark M. Effects of psychosocial interventions with cancer: a selective review of the literature. Health Psychol 1995; 14: 101–8.
13. McIntosh J. Processes of information seeking and control associated with cancer: a selective review of the literature. Soc Sci Med 1974; 8: 167–87.
14. Maguire P, Roe P, Goldberg D, Jones S, Hyde C, O'Dowd T. The value of feedback in teaching interview skills to medical students. Psychol Med 1978; 8: 695–704.
15. Maguire P, Booth K, Elliott C, Jones B. Helping health professionals involved in cancer care acquire key interviewing skills, the impact of workshops. Eur J Cancer 1996; 32A: 1486–9.
16. Maguire P, Fairbairn S, Fletcher C. Consultation skill of young doctors I: benefits of feedback training in interviewing as students. Br J Clin Res Ed 1986; 292: 1573–6.
17. Maguire P, Fairbairn S, Fletcher C. Consultation skills of young doctors II: most young doctors are bad at giving information. Br J Clin Res Ed 1986; 292: 1576–8.
18. Degner L, Russell CA. Preferences for treatment control among adults with cancer. Res Nurs Health 1988; 11: 367–74.
19. Beaver K, Luker KA, Owen RG, Leinster SJ, Degner LF. Treatment decision making in women newly diagnosed with breast cancer. Cancer Nurs 1996; 19: 8–19.
20. Wilkinson S, Roberts A, Aldridge J. Nurse–patient communication in palliative care: an evaluation of a communication skills programme. Palliat Med 1998; 12: 13–22.
21. Krishnasamy M, Plant H. Developing nursing research with people. Int J Nurs Res 1998; 35: 79–84.
22. Corner J, Plant H, Warner L, A'Hern R, Bailey C. Non-pharmacological intervention for the management of breathlessness in lung cancer. Palliat Med 1996; 10: 299–305.
23. Bailey C. Ethical issues in multi-centre collaborative research on breathlessness in lung cancer. Int J Palliat Nurs 1996; 2: 95–101.